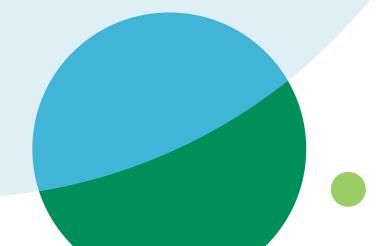




 A Resource Guide for HIV/AIDS Programs



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## 1

### Starting Up:

First Steps towards the Integration of Viral Hepatitis into HIV/AIDS/STD Programs

### **Starting Up:**

First Steps towards the Integration of Viral Hepatitis into HIV/AIDS/STD Programs

ntegration of viral hepatitis into existing services has become a major goal of many HIV/AIDS/STD programs.

logic for such integration is sound organizationally and from the perspective of public health, considering that HIV and hepatitis B and C are bloodborne pathogens that are transmitted in similar ways and can be prevented by common interventions; similarly, hepatitis A, B, and C impact many of the same populations as HIV. The existence of a well-developed HIV/AIDS/STD infrastructure presents a prime opportunity to address viral hepatitis efficiently and effectively. Integration fosters an approach that maximizes the health of the public as well as of individuals by proactively offering testing, counseling, referral, and other services to high-risk individuals as well as conducting surveillance and other core public health functions.

Nonetheless, the introduction of such a broad new area of focus into HIV/AIDS/STD programs does not "just happen" but rather entails a sometimes complex and lengthy process. Working with programs throughout the country, NASTAD has identified a number of steps, outlined in this document, that various jurisdictions have taken to start the integration of viral hepatitis into their programs. The steps outlined in this document should not be regarded so much as a roadmap – to be followed in only one way, in one direction, at one pace – but rather as a menu of options. While we have ordered this document in a sequence that has been followed in a number of

The Integration of Viral Hepatitis into HIV/AIDS Programs:

successful attempts at integration, different programs will find themselves in different circumstances and with different needs, possibilities, and limitations. The distinct steps identified by NASTAD are:

### IDENTIFYING STAKEHOLDERS AND WORK GROUP DEVELOPMENT:

The experience of combating HIV has amply demonstrated the need for engaging members of impacted communities as well as public health professionals and care providers. Those with a strong interest in the development of viral hepatitis programs, "stakeholders" in the issue, should be involved from the ground-level up in the development of plans for integration. One effective approach for involving stakeholders is to include them on a work group.

#### **Needs Assessment:**

Although HIV/AIDS/STD programs may have a good anecdotal sense of the needs of their jurisdiction in terms of viral hepatitis, thorough planning often requires a more systematic and comprehensive needs assessment. Such a needs assessment can serve as the empirical basis of a program tailored to a jurisdiction's most pressing concerns. A needs assessment may be undertaken by a department of health or perhaps by a stakeholders' work group.

### WHITE PAPER AND STRATEGIC PLAN DEVELOPMENT:

A work group can provide opinions and informed viewpoints and a needs assessment can provide facts, but at some point jurisdictions may wish to weave these into a unified public health strategy. A white paper presents a strategy for how to address an issue at hand. It provides a framework from which to begin adapting and/or building infrastructure. Similarily, a strategic plan is a method that can be used to convey a public heath strategy as well as to help foster consensus on the most pressing needs within a jurisdiction. Strategic planning can provide a clear vision that helps the various stakeholders from working at cross-purposes.

#### SECURING LEGISLATION AND/OR FUNDING:

Programs obviously cannot function very well, or for very long, without the necessary public health authority and sufficient funding needed to implement programs. The preceding steps of identifying stakeholders, convening a group, conducting a needs assessment and publishing a strategy document can demonstrate the need for new

legislation and/or funding. However, in some jurisdictions, there may also be impetus from legislators themselves and/or from community advocates for legislation and funding. Therefore, some HIV/AIDS/STD programs may find themselves conducting their integration programs as a result of legislation rather than as a precursor to it. Nonetheless, the preceding steps may also be of use to jurisdictions in this situation.

# Identifying Stakeholders and Work Group Development

he involvement of key stakeholders is a necessary first step towards addressing viral hepatitis issues. Whether the goal is to integrate viral hepatitis into a specific program or to develop a state plan to address viral hepatitis, stakeholder involvement and support are critical to ensure the success of the proposed activity.

### WHO ARE THE STAKEHOLDERS FOR HIV AND VIRAL HEPATITIS INTEGRATION?

Stakeholders are people that have an investment in an issue. Integration stakeholders include people that are involved professionally or personally with activities either directly or indirectly related to HIV, STDs, and viral hepatitis. For example, integration stakeholders may include people who are infected with viral hepatitis, people who provide services to people infected with or atrisk for viral hepatitis, and people with expertise in evaluation or surveillance. If you are designing, implementing, and evaluating an integration program, stakeholders could include the people that will be administering the program, evaluating the program, and using the program.

#### HOW CAN STAKEHOLDERS BE IDENTIFIED?

Integration stakeholders can be found by drawing on individuals and organizations that are directly addressing viral hepatitis, HIV, and STD issues, and through organizations that are affected by viral hepatitis, such as substance abuse treatment organizations and corrections. Consider which individuals and/or organizations are needed to develop an effective integration strategy, and utilize established working relationships and seek referrals from professional contacts.

The Integration of Viral Hepatitis into HIV/AIDS Programs:

#### WHY IS STAKEHOLDER INVOLVEMENT IMPORTANT?

Stakeholder involvement ensures the appropriateness and credibility of proposed integration activities. Stakeholders bring an expertise to the integration process, which increases the likelihood of successful planning and development. Involvement of stakeholders also promotes a more inclusive approach to public health that is not only "top-down" from officials to impacted communities and individuals but also incorporates valuable "bottom-up" input and insight.

#### HOW IS STAKEHOLDER SUPPORT GAINED?

## recommendations from jurisdictions

- Consider what people are needed to ensure the success and credibility of integration activities, and invite them to be a part of integration planning.
- Do not close the door to anyone.
   Everyone provides something valuable and needed to the process.
- In order to secure support from apprehensive stakeholders, utilize other credible stakeholders that have "bought-in."
- In order to secure support, share examples of successful integration activities from other communities.

Stakeholder support for integration will likely fall across a continuum of those who are very enthusiastic and some who are very hesitant. The stakeholders eager to begin integration should be invited into the process at the beginning. Stakeholders that fall in the middle of the continuum may be swayed to support integration efforts by those that have already "bought-in." There are many reasons why individuals may be reluctant to get involved with integration activities. Stakeholders may feel that working on viral hepatitis issues presents a conflict of interest, or is a burdensome addition, to their respective programs. When stakeholders are hesitant, learn the reasons behind their reluctance and work with them individually to address their concerns. Sharing examples of successful integration projects and discussing what is expected of the stakeholder may help alleviate some hesitation. If reluctant stakeholders are willing, invite them to present their concerns to other stakeholders so that a dialogue around possible solutions can begin.

One state health department garnered support from a hesitant key stakeholder by presenting the issue in a fun, engaging format. All key stakeholders at the department were invested in addressing hepatitis C issues except the director of health whose support was crucial for success. To assure that the director and others had state of the art knowledge and understanding of hepatitis C, members of the department developed an educational and interactive game to increase awareness of hepatitis C and to show how

### Profile of

### THE HOUSTON DEPARTMENT OF HEALTH AND HUMAN SERVICES' INTEGRATION OF HEPATITIS C SERVICES INTO STD CLINICS

The Houston Department of Health and Human Services (HDHHS) determined that the most cost-effective and efficient way to provide hepatitis C counseling and testing services would be to integrate services into existing STD clinics. STD clinics provided the most ideal setting for integration because of the existence of a counseling and testing infrastructure and the opportunity to access individuals that might be at risk for hepatitis C.

Four Houston clinics were targeted for integration, and HDHHS then sought support and input from key stakeholders at the clinics to design the integrated program. In order to determine "key stakeholders," HDHHS staff first identified clinic service areas that would be directly affected by the addition of hepatitis services. They then generated a list of people working in those service areas, and invited the named representatives to join the planning group. The role of the group was to examine what changes and additional steps the integration process would require and determine how to effectively integrate hepatitis C services into the existing clinic setting as smoothly as possible.

In the initial groups' planning meetings, HDHHS found that while all staff were eager to begin providing hepatitis C services, there were concerns about the additional amount of paperwork and of the added time to the patients stay at the clinic. HDHHS encouraged all staff members to share their concerns and to raise their questions, stressing that the planning group was a collaborative process and all opinions were crucial to effective program development. The staff "bought in" to the process because they had a voice that was valued in the planning and development of hepatitis C integration. In addition, the planning group continued to meet and discuss the process of implementation after hepatitis C services were integrated into the clinics. Planning group members discussed what was working with the implementation and what needed to be adjusted. This constant attention to the quality of the process helped ensure a successful integration.

### identifying stakeholders

- Generate a list of what agencies are currently working on viral hepatitis issues.
- Generate a list of what agencies are impacted by viral hepatitis.
- Generate a list of individuals/organizations that have expressed an interest in viral hepatitis and HIV and STD integration issues.
- Generate a list of organizations/individuals whose support and/or resources are needed in order to effectively integrate.
- Determine a contact person for each listed agency.
- Consider what contact people have access to or credibility with high-risk communities and with policy makers.
- Ask each contact person to name individuals or organizations that should be included in viral hepatitis and HIV and STD integration planning. Exhausting the lists of stakeholders helps ensure that all key stakeholders are included. It is also important to give this process continued attention throughout the integration process to ensure that all key stakeholders are at the table.

### securing stakeholder support

How to gain stakeholder support will vary based on what the stakeholder is being asked to support. Stakeholder support could be needed for something specific, such as a project to integrate hepatitis C testing with HIV testing, or it could be more general, such as joining a work group to address the issue of viral hepatitis integration. The following are general points to consider:

- Generate a list of what agencies are currently working on viral hepatitis issues.
- Utilize "opinion leaders," or stakeholders that have considerable influence among their peers, to gain the support of reluctant stakeholders.
- Utilize examples of effective and successful integration activities from other jurisdictions to help secure stakeholder support.
- Carefully consider what information the reluctant stakeholder would need to buy-in. If the stakeholder is concerned about demands on staff, demonstrate how these demands would be alleviated or addressed. If the stakeholder is concerned about the financial burden, demonstrate how this concern will be addressed. Tailor your message to the individual's specific concern(s).

The Integration of Viral Hepatitis into HIV/AIDS Programs:

hepatitis C fits in with other department programs. Their strategy was successful.

Once key stakeholders are identified and supportive, the development of a viral hepatitis work group is a possible next step. A work group provides a venue for individuals invested

in the issue to come together to collectively determine goals, objectives, and action steps. Work groups can help plan, advise, and monitor viral hepatitis integration activities.

# recommendations from jurisdictions

- Seek out individuals who are invested in the issue, but also those who possess commitment, capacity, and the willingness to cooperate.
- If possible, secure a travel budget to ensure participation from individuals throughout the state.
- Keep the work group small to ensure focus on particular issues.
- Establish clear objectives and a clear focus.
- Do not underestimate the role of the facilitator. A capable facilitator is necessary to keep the work group on task.

### WHAT IS A VIRAL HEPATITIS INTEGRATION WORK GROUP?

A work group is comprised of people that come together to develop a response or a strategy to a concern or issue that all members of the group share. For our purposes, group members would include key stakeholders in viral hepatitis, HIV, and STDs. Group members may provide specific expertise in addressing viral hepatitis integration, and/or group members may be affected by the issue of integration.

#### WHY ARE WORK GROUPS IMPORTANT?

Work group development is an important strategy because it allows for key players of a particular issue to come together to generate solutions or action steps for a problem. Work groups bring people

together to develop a unified response to the issue at hand, and allow for members of various organizations to provide their expertise and opinions. Work groups can successfully address issues because they combine people, resources, and provide social organization.

#### HOW DO YOU DEVELOP A WORK GROUP?

Work groups can range from very informal to very formal. An organization or individual must take the lead in inviting potential members and hosting initial meetings. Once a group of individuals are committed to participating, the group can determine the rules, leadership style, and the mission of the work group. There is no standard way for a work group to operate. For example, some work groups elect a chair to facilitate the meetings, while other work groups prefer to rotate facilitators meeting-to-meeting.

# PROFILE OF THE COLORADO DEPARTMENT OF HEALTH'S VIRAL HEPATITIS PROGRAM

In 1999, in response to increasing awareness of hepatitis C in Colorado, the Colorado Department of Public Health and Environment (CDPHE) initiated an internal workgroup, the "viral hepatitis crosscutting team." This team consists of members of STD, HIV, communicable disease, surveillance, and immunization programs. They began meeting on a monthly basis to strategize how to best integrate and address viral hepatitis issues as a state health department. This group of internal stakeholders is now working with a larger group of external stakeholders to develop a CDPHE strategic plan for viral hepatitis integration. The viral hepatitis crosscutting team now meets to review and analyze the feedback from internal and external stakeholders, prioritize critical issues, identify target risk groups, and establish goals and objectives. The plan that they develop will be brought to the larger group of external stakeholders, and the larger group will assist the department in determining priorities and action steps.

In September of 2000, the Viral Hepatitis Program was established to hepatitis prevention centralize activities in the Disease Control and Environmental Epidemiology Division. The Program includes the hepatitis previously activities in the Immunization Program, and newly funded hepatitis C activities. Program seeks to promote the prevention of viral hepatitis by increasing disease awareness and prevention options; disseminating educational materials about services: communicating strategies for detection and treatment; designing screening protocols and providing information and referral services.

Activities currently underway within the program are perinatal hepatitis B case management, hepatitis immunization outreach to at-risk populations, hepatitis C prevention awareness and promotion. The program is also working on collaborative projects with Denver Health and the Hep C Connection. These projects are designed to integrate hepatitis prevention messages into existing services in the STD/HIV clinics and correctional facilities; and to provide information and services to those who are infected. Many new projects will begin in the months to come and the program will expand its capacity to analyze hepatitis morbidity data.

# PROFILE OF THE TEXAS DEPARTMENT OF HEALTH'S HEPATITIS C WORK GROUP 1

In 1998, epidemiologists at the Austin/Travis County Health and Human Services (ATCHHS) Department and the Texas Department of Health (TDH) Infectious Disease, Epidemiology & Surveillance (IDEAS) Division, became concerned about an increase in reported cases of hepatitis C in Travis County. They decided to convene an informal work group to closely examine the issue.

Representatives invited to join the informal work group included members of Hep C Connection of Colorado, the Texas Medical Association (TMA), the blood bank industry, the Texas Department of Criminal Justice (TDCJ), and employees in the IDEAS Division within the Bureau of Communicable Disease and in the TDH Bureau of HIV & STD Prevention. The group decided to draft a white paper examining the issue of the increasing number of hepatitis C cases in Texas and its effects on the state. The white paper was later used as the basis for hepatitis C legislation.

In the spring of 1999, the informal group continued to meet and grow as word-of-mouth encouraged additional participation. In June of 1999 the group became a formal work group.

By the fall of 2001, the state work group consisted of approximately 190 members. Representatives of state and local health departments, TMA, TDCJ, nonprofit clinics, advocacy groups, and blood and tissue centers are all part of the work group. Others who attend include health care professionals,

patients, health education specialists, HIV counselors, outreach workers, legislative staff, church leaders, and pharmaceutical company representatives. Several members are out-of-state members who participate through email correspondence.

The work group now meets quarterly and serves as an advisory work group to TDH staff in implementing the hepatitis C legislation. Two working subcommittees were formed in the spring of 2000: a Population General Education Subcommittee and Professional Education Subcommittee. Both subcommittees have drafted mission statements, goals, and strategies.

The subcommittees meet between work group meetings. They resolve issues brought forth by the larger work group, research issues for the larger work group, and plan the proposed projects. The working subcommittees report back to the larger work group quarterly.

TDH IDEAS staff are responsible for coordinating the larger work group and the two subcommittees. Staff schedule and facilitate the meetings, record minutes, maintain email correspondence, and serve as a liaison among the work group members. The work group minutes, meeting notices, and agendas are emailed to all work group members.

### work group development

- Determine who is needed to be a part of the work group to ensure a comprehensive group that can address all issues presented by viral hepatitis integration.
- Generate and circulate this list among stakeholders to confirm thoroughness.
- Invite potential members to join.
- As a group, determine the mission statement, goals, and objectives of the work group.
- As a group, determine the leadership, rules, and roles of the group members.
- As a group, continually reassess whether all needed stakeholders are at the table.

### Needs Assessment

nce stakeholders have been identified and a work group is formed, there are many different strategies that the work group can use in order to address viral hepatitis issues in their jurisdiction. The history, circumstances, resources, and capacity of each jurisdiction will all play a part in determining which approach to take. The following examples of conducting a needs assessment, writing a white paper, and developing a strategic plan present strategies that some jurisdictions have used to respond to viral hepatitis.

#### WHAT IS A NEEDS ASSESSMENT?

A public health needs assessment is a process used to determine the current status and needs around an issue for a defined population or geographic area.<sup>2</sup> process involves collecting and analyzing primary and secondary data related to a particular topic. For example, a viral hepatitis needs assessment would include a review of state epidemiologic data on hepatitis, a review of the existing literature on hepatitis, and the collection of information from individuals and service providers affected by hepatitis. A needs assessment can be thought of as exploratory: it involves the collection of information to gain a greater understanding about a topic and can vary in scope. A broad needs assessment could examine what is needed to integrate viral hepatitis prevention and care into an existing public health infrastructure within a jurisdiction. A smaller needs assessment could specifically look at the needs related to developing a referral and care network for individuals infected with hepatitis C. For our purposes, we will concentrate on the steps needed to conduct a broad needs assessment.

The Integration of Viral Hepatitis into HIV/AIDS Programs:

#### WHY IS A NEEDS ASSESSMENT IMPORTANT?

A needs assessment determines what current resources, programs, and funding are in existence and what are lacking around an issue area. The review of available secondary data and the collection of primary data can help determine

## recommendations from jurisdictions

- Develop a plan for conducting the needs assessment before beginning the process.
- If there is no funding to conduct the needs assessment, consider using volunteers from local universities that may need to fulfill research requirements.
- Include representatives from local agencies in the planning of the needs assessment to ensure the credibility of the process.
- Involve individuals in the planning process from the communities that are affected.
- Pilot interview questions prior to beginning the needs assessment to ensure that your interview guides are effective.
- Employ process evaluation measures to ensure that the needs assessment is being conducted true to plan.
- Don't be afraid to adjust your plan in the middle of the process; the goal is finding the information that you are seeking, and flexibility is important.

what programs and resources are needed and feasible to comprehensively address an issue. This allows the public health community prioritize to issues and develop well-informed effective. strategy. A viral hepatitis needs assessment is also important because of the dearth of data available; a needs assessment provides a focused, systematic plan collecting data comprehensively understand the needs across an issue.

## WHO SHOULD BE INVOLVED IN CONDUCTING A NEEDS ASSESSMENT?

Α needs assessment planning committee or work group should comprise individuals with some connection to the issue being assessed. Members should bring an area of expertise to help inform the assessment process. For example, a viral hepatitis needs assessment would include people that have

access to individuals that may be interviewed, people that can provide data and statistics, people that can help design and conduct the needs assessment, and people with expertise in data analysis. If funding is available, consultants may also be retained to provide technical expertise.

# PROFILE OF THE MAINE BUREAU OF HEALTH'S HEPATITIS C NEEDS ASSESSMENT<sup>3</sup>

In 1997, in response to reports of hepatitis C infection from the medical provider and grass roots public health community, the Maine Bureau of Health initiated mandatory case reporting of chronic HCV infection and began a case registry. The Bureau of Health also convened a hepatitis C working group, which evolved from a group of people working in the HIV community who were seeing a large number of clients infected with hepatitis C. Initially, members of the hepatitis C working group included clinicians, patient advocates, and public health professionals. The group met quarterly to discuss and strategize the state's response to hepatitis C. The group first concentrated their efforts on educating medical providers about hepatitis C, but over time determined that a formal approach was needed to develop a comprehensive response to hepatitis C in Maine. Due to the dearth of information on hepatitis C, the group then decided to conduct a statewide needs assessment in order to gain baseline data to inform a state hepatitis C strategy.

The Bureau of Health then convened a subcommittee of the working group to design the needs assessment. The needs assessment steering committee ultimately included individual members of the hepatitis C working group and other invited participants from the Department of Human Services, Bureau of Medical Services, Maine Center for Public Health. the Department of Corrections, and the Department of Mental Health, Mental Retardation, and Substance Abuse Services. The work group developed a plan for the needs assessment, and obtained funding through the Bureau of Health and through pharmaceutical companies. This funding was used to hire a consultant to conduct the needs assessment.

The needs assessment was conducted over a four-month period. The consultant focus conducted groups, utilizing convenience sampling techniques, of representatives from the Office of Substance Abuse, the Department of Corrections, AIDS service organizations, and a hepatitis C community support group. The consultant also conducted individual interviews twenty with representatives from Maine AIDS service organizations, hepatitis C primary care providers, and hepatitis C patients from across the state. Two surveys were also administered in collaboration with other agencies: a national survey of prison medical doctors and a survey of a sample of primary health care providers and gastroenterologists in Maine.

Other data collected included a review of Maine hepatitis C epidemiologic surveillance data and hepatitis C health care expenditure data; a review of the public health literature; and phone interviews with public health officials from other states.

After the assessment was conducted, the results of the needs assessment were presented to the steering committee who developed recommendations for the course of action to be taken by the state. These results of the needs assessment and the steering committee's recommendations are now being used to inform the state legislature about possible strategies to address hepatitis C in Maine.

### designing a needs assessment <sup>4</sup>

Please note the following action steps are meant to be illustrative rather than exhaustive.

- Consider what questions you would like the needs assessment to answer. These questions will guide the needs assessment. For example, the Maine Bureau of Health was interested in learning the status of hepatitis C infection prevention and care in Maine. These questions led the researchers to find whether resources, such as hepatitis C counseling, testing, and medical care, were available in Maine, and to further investigate the state of the services that were available.
- Determine which sources of data (e.g. primary and secondary) would be best to utilize in order to answer specific questions. Secondary data can provide information on existing programs and epidemiology, and primary data can be used to expand on these data and answer questions that may emerge from the secondary data.
- Determine the best way to obtain the needed data. For example, with secondary data this would involve determining where and how data can be collected. There may be substance abuse agencies or other health care facilities that have been collecting information on patients that are infected with hepatitis, and they may be willing to share this information. For primary data, this would involve deciding what format (e.g. focus group, survey, individual interview) and what sampling strategy (e.g. probability, convenience, purposive) would be the most appropriate and efficient way to collect data.
- When you collect primary data, determine whether you will collect qualitative and/or quantitative data. It is strongly recommended that you collect both types of data. Quantitative data require that you use standardized measures that have predetermined response categories. This allows the investigator to assign numbers to the response categories and to perform statistical analyses on the data set. Quantitative measures would include surveys with predetermined response categories and interview guides that utilize close-ended questions. Qualitative data provides in-depth information on a limited number of people;

this information increases understanding of the participants and/or issue studied, but is not generalizable to the larger population. Qualitative measures 19 include focus group and interview guides that utilize open-ended questions. Collecting both qualitative and quantitative data will provide a deep, rich picture of the issues that are being examined. For example, Maine surveyed a sample of state primary care practitioners and gastroenterologists to ascertain their level of knowledge, attitudes, practices, and beliefs for managing people with hepatitis C infection. This information provided a picture of medical practitioners across the state, and allowed for comparisons between both types of medical professionals. Maine also conducted interviews with medical specialists providing care to people with hepatitis C infection, and this allowed for a more in-depth understanding of the barriers and challenges they face in their practice.

- When collecting primary data, it is important to consider the appropriate sampling strategy. A probability sample enables one to make generalizations from the sample to the larger population. This design will only be realistic when there is a large population which can be enumerated from which to draw a sample. For example, Maine was able to draw a random sample of primary care practitioners in the state using lists of the entire population of state primary care practitioners provided by the Maine Board of Nursing and the Maine Board of Licensure. In comparison, it is difficult to draw a random sample of individuals to participate in focus groups and interviews. For example, if you are seeking information on injection drug users, it would be impossible to conduct a random sample because the total population of injection drug users in Maine is unknown. It is more likely that you will conduct a focus group or interviews by going to places where you know you can find injection drug users and asking for an interview. This is utilizing purposive sampling.
- Develop an interview and/or focus group guide and decide on appropriate settings and facilitators (if time permits, pilot test interview questions to ensure that your questions are eliciting the types of responses you intend). Focus efforts on obtaining information in the most concise and efficient way. For example, if you would like to obtain information from former injection drug users, consider utilizing methadone maintenance clinics to pilot test questions and/or hold focus groups. Patients in the clinic may be willing to linger in the clinic to answer a survey or participate in a focus group.
- Determine whether incentives/compensation will be provided to interview participants.
- Submit focus group and interview guides to the health department's Institutional Review Board (IRB) for approval.

### conducting the needs assessment

- Assign responsibilities for data collection. It is possible to have one primary investigator who conducts all interviews, collects all secondary data, and administers all surveys. A primary investigator could be secured with funds or a volunteer investigator, from a local university for example, could be obtained. Several people could also be responsible for collecting the different pieces of data. With individual interviews and focus groups, it is important that fidelity to the interview guides is maintained across different investigators.
- Utilize professional and community contacts that can provide entrée to individuals and/or groups from whom you would like to collect data.
- Conduct a "resource inventory." This involves listing in all of the services available in the community or geographic area to which the needs assessment is confined that provide services and/or expertise related to the issue area.

# analyzing and presenting the results of the needs assessment

### analyzing the results

- Check each piece of data for completeness to determine if it can be included in the data set.
- Utilize individuals in the health department that have experience analyzing qualitative and quantitative data. Sophisticated data analyses will require statistical software, but frequencies and comparison measures can be run without the aid of software. Qualitative data analysis requires transcription of the interviews and considerable time to read through the data and identify major themes. Consider using EZ-Text<sup>5</sup>, a free qualitative data analysis program offered by the CDC, to help sort and analyze the data.
- If resources permit, have more than one person analyze both the qualitative and quantitative data to ensure reliability.
- Return to the resource inventory conducted and identify whether these resources are meeting the needs identified in the data. Clearly outline where there is unmet need.

### presenting the results

- In the written report, include at minimum the following chapters: introduction, methodology, results, and conclusions/recommendations. Also provide an executive summary, and appendices of survey instruments used and other information that would help explain to the reader the process.
- Present the results at a meeting that draws all of the stakeholders together.
   Steps for the next course of action can then be developed.

# White Paper and Strategic Plan Development

white paper is an additional strategy that can be used to advance a public health response to viral hepatitis. A white paper differs from a needs assessment in that it outlines a clear strategy that can be used to address a specific issue. A white paper presents available data to support a particular viewpoint, but does not involve primary data collection.

#### WHAT IS A WHITE PAPER?

A white paper communicates a position by presenting evidence and proposing solutions based on existing data and resources. It is a brief and concise paper that outlines an issue and presents a strategy to address the issue. For example, a viral hepatitis integration white paper could present the issue of integration with HIV/STD programs, provide the evidence that supports integration (e.g. shared target populations, similar prevention messages, cost-effectiveness), and propose a strategy on how to effectively integrate programs.

#### WHY IS A WHITE PAPER IMPORTANT?

A white paper is a medium that can be used to present an argument and offer solutions. It is a succinct paper that provides the reader with a problem, offers evidence to support the problem, and presents a strategy on how to best address the problem. Its goal is to persuade the reader, and to effectively convey the strategies supported by an organization or work group addressing the particular issue. A white paper can be used to influence individuals in decision-making roles on how to respond to an issue.

The Integration of Viral Hepatitis into HIV/AIDS Programs:

#### WHO SHOULD BE INVOLVED IN WRITING A WHITE PAPER?

Who is involved in the production of a white paper will vary based on the messages conveyed and the strategies proposed. For example, the Texas Department of Health's (TDH) hepatitis C white paper was drafted by members of TDH, because the paper presented strategies that TDH could use in order to address hepatitis C infection in Texas. It is recommended that a small number of people are involved in the development of the white paper, and that the paper is reviewed by a larger group of people that have expertise in the issues presented in the paper.

A white paper presenting a public health strategy can be the impetus needed to advance policies or a program. It is smaller in scale than a strategic plan. A strategic plan also

### recommendations from jurisdictions

- If the paper is framed as "the response of public health," the state health department should take the lead on developing and writing the paper.
- A white paper enables you to present your solutions to the problem at hand.
- Think of a white paper as a vehicle to market what you believe is the solution to a problem at hand.
- Share the white paper with experts that can offer you advice on the content and the presentation.

communicates a public health strategy, but the development process is more time-intensive, its recommended actions are limited to what is feasible within a certain time frame, and a broader range of stakeholders may be involved.

#### WHAT IS A STRATEGIC PLAN?

A strategic plan is a written document that requires participants to detail a problem and strategize how to best address the problem within a certain time frame. Strategic planning enables people to clearly define the purpose of what they are doing and to establish goals and objectives consistent with that mission. A strategic plan results in fundamental decisions that shape and guide an organization or group's response to an issue. Strategic planning is necessary when a change from current

practices is needed or anticipated. The emergence of hepatitis C as a major public health challenge is proving to be of sufficient magnitude and complexity that some jurisdictions feel the need for a full-scale strategic plan.

### PROFILE OF

### THE TEXAS DEPARTMENT OF HEALTH AND HUMAN SERVICE'S WHITE PAPER:

"HEPATITIS C: AN EMERGING HEALTH CONCERN FOR TEXANS" 6

In 1998, the Texas Department of Health (TDH) convened an informal work group to address growing concerns around the prevalence of hepatitis C in Texas. The informal group included representatives from hepatitis organizations, the Texas Medical Association (TMA), the blood and tissue industry, the Texas Department of Criminal Justice (TDCJ), and employees from the Infectious Disease, Epidemiology & Surveillance Division (IDEAS) within the Bureau of Communicable Disease and employees in the TDH Bureau of HIV & STD Prevention.

The work group determined that writing a white paper would be an effective way to convey information, demonstrate need, and provide recommendations for a public health response to hepatitis C in Texas. The white paper recommended specific actions needed for TDH to enhance the state's public health infrastructure to include prevention, counseling, and treatment for hepatitis C. The white paper includes information on epidemiology, testing, and emerging treatments on the market for hepatitis C. It also provides estimates on screening and counseling costs.

The white paper was shared with Texas Rep. Glen Maxey (D-Austin), who used this information to draft House Bill (HB) 1652. He presented HB 1652 to the 76th Texas Legislature, which passed the bill and appropriated approximately \$3 million for the next biennium for implementation.

## writing a white paper

- Carefully consider your audience. How are their interests involved? What evidence is likely to engage them?
- Frame your paper to appeal to the audience you would like to persuade.
- Gather data to support your argument.
- Keep your recommendations simple and direct.
- Provide data to back up your recommendations.
- Disseminate your paper to key policy makers and opinion leaders.

#### WHY IS A STRATEGIC PLAN IMPORTANT?

A strategic plan allows for a group or organization to clearly communicate their goals and objectives to the community, policy makers, and funding agencies. It allows a group to assess needs, clarify purpose, prioritize issues, strategize future directions, and develop a

recommendations from jurisdictions

- Seek out stakeholders to be a part of the strategic planning process.
- Consider using a steering committee as a strategy to bring all stakeholders into the planning process.
- Involve individuals from community-based organizations and those infected with hepatitis.
- Seek funding to help cover the costs for individuals from organizations without money to fund their participation.
- Split the process up using subcommittees to ensure that individual issues are given the focus and attention needed.

coherent basis for decision-making. the addition, process developing a strategic plan allows time for the development consensus and the obtaining of "buy-in" from diverse parts of a community. A strategic plan also provides a base for which progress be measured. Strategic can planning begins with a broad goal and ends with the development of specific action strategies.

### WHO SHOULD BE INVOLVED IN THE PLANNING?

People who have an investment and expertise on the issue at hand should be involved in the strategic planning process. A strategic plan hepatitis addressing viral integration would include all key stakeholders from within the iurisdiction's public health establishment involved with viral hepatitis. These would include but not be limited to representatives from STD, HIV, substance abuse agencies, corrections, surveillance, and immunization. Stakeholders

may often also include representatives from impacted communities, including advocacy organizations, service agencies, support groups, and people living with the disease. In the case of HIV/AIDS, the inclusion of people living with HIV/AIDS in planning processes has become a key tenet, both because it empowers these individuals and also because of the important first-hand information and insight that they can provide.

The Integration of Viral Hepatitis into HIV/AIDS Programs:

Individuals involved in the strategic planning process may vary in the amount of participation and investment of time dedicated towards crafting the plan. For example, in Colorado, the Colorado Department of Public Health's (CDPH's) strategic planning process has divided roles among the internal (employees of the health department) and external (e.g. hepatitis community based organizations, AIDS service organizations, substance abuse agencies) stakeholders. First the internal and external stakeholders met together and hired a facilitator to lead the meeting. At this meeting they reviewed existing data available on viral hepatitis for Colorado and the nation, reviewed the resources that they currently have in place or have the capacity to develop to address viral hepatitis, and conducted a gap analysis to determine the challenges and obstacles. The internal stakeholders are now meeting to prioritize the critical issues and to develop specific goals and objectives. Once that process is completed, the internal stakeholders will bring their suggestions to the larger group for discussion and feedback.

### Profile of California's Hepatitis C Strategic Plan 7

In 1999, California determined that a strategic planning process was needed to develop a state response to hepatitis C. The California Department of Health Services (CDHS) and local health officials identified key stakeholders across the state to participate in the planning process. This "steering committee" met twice to outline the problem, to conduct a resource inventory of the hepatitis C services and activities across the state, and to identify major challenges and obstacles. The steering committee also identified five primary themes on which focus their efforts: to primary prevention, secondary prevention, professional and public education and training, surveillance and research, and long-term care and rehabilitation. The members of the steering committee then reviewed existing information on hepatitis C and drafted problem statements, ideas for a vision and mission, and suggested other groups to include in the planning process.

Additional participants joined the steering committee to form the Working Group, and two, two-day sessions of the Working Group were held. National and state experts were invited to provide current information on hepatitis C. The Working Group then refined the steering committee's problem statements, mission, and vision, and developed guiding principles.

In order to effectively address diverse issues, the Working Group then divided into five small task groups based on the identified five goal areas. Each task group developed a goal statement,

objectives, and action steps to address the identified goal. After each small group meeting, the larger group reconvened to discuss the recommendations and actions of each task group and to come to consensus on the proposed actions.

The Working Group decided to prioritize the objectives based on the ability and capacity of the partners to address them within the three-year plan. The Working Group assigned the highest priority to the objectives considered to be the most critical in order to reach the goal of preventing transmission of hepatitis C and reducing transmission from those already infected.

The Working Group then recommended which high priority, key issues would be included in the three-year plan, and the result was a comprehensive strategic plan, which includes the mission, vision, guiding principles and five goals, with objectives and action plans for each. The plan presents a strategy with suggested actions that California partners and stakeholders can take to address hepatitis C. The goals, objectives, and action steps outlined in the plan are recommendations from the Working Group to the CDHS. The entire strategic planning process took a year to complete, and has given those working on hepatitis C issues across the state a common logic and shared objectives. It should be noted that independent of this planning process, state legislation was passed which allocates funding for hepatitis C outreach, screening, and education; the strategic planning process helps ensure that the funds will be used effectively and coherently across the state.

## writing a strategic plan

The following suggested steps are drawn from strategic planning models for non-profit organizations <sup>8,9</sup> and from the processes used by California and Colorado. This is just one possible approach that can be taken to develop a strategic plan.

- Identify key stakeholders and form a work group.
- As a work group, assess the strategic planning process and determine whether you have the capability, commitment, and time to embark on the process. Strategic planning takes considerable time and energy. If the work group is unsure about their ability to undertake the process, the group should consider directing their energies towards other activities, such as developing a white paper, collecting information on hepatitis providers, conducting a resource inventory, etc.
- Identify specific issues that the work group should address in an agreed upon time frame. For example, California's overall goal is to prevent transmission of hepatitis C and reduce transmission of those already infected, but five primary goal areas were identified in order to narrow the focus and allow for realistic outcomes within the defined three-year time frame. The five goal areas that California identified were primary prevention, secondary prevention, professional and public education and training, surveillance and research, and medical management and rehabilitation.
- Clarify the roles of the members of the work group in the planning process. California's strategic planning process was initially led by a steering committee, who then invited partners across the state to join a Working Group. The larger Working Group was then split into five smaller task groups in order to address the identified five goal areas. In Colorado, the Colorado Department of Health's strategic planning process has divided roles among the internal (employees of the health department) and external (e.g. hepatitis community based

organizations, AIDS service organizations, substance abuse agencies) stakeholders. First the internal and external stakeholders met together and hired a facilitator to lead the meeting. At this meeting they reviewed existing data available on viral hepatitis for Colorado and the nation, reviewed the resources that they currently have in place or have the capacity to develop to address viral hepatitis, and conducted a gap analysis to determine the challenges and obstacles. The internal stakeholders are now meeting to prioritize the critical issues and to develop specific goals and objectives. Once that process is completed, the internal stakeholders will bring their suggestions to the larger group for discussion and approval.

- Identify the information that must be collected in order to make sound decisions. Key components of a strategic plan include a mission statement, a vision statement, a resource inventory, and an assessment of needs.
- Develop a mission statement. A mission statement should articulate the purpose of the group and what it seeks to accomplish; the main activity through which the group works to fulfill this purpose; and the principles or beliefs that guide the group. A mission statement is a clear message that provides a focus and foundation for the group.
- Develop a vision statement. A vision statement articulates what success would look like for the group. For example, California's vision statement states: "The vision for hepatitis C prevention and control is a coordinated local and statewide effort supported by public and private partnerships providing comprehensive, science-based hepatitis C services that assures:
  - 1. Affordable and accessible hepatitis C counseling, screening, education, treatment, harm reduction and prevention efforts are available to all persons in need;
  - 2. Education of all patients, providers, policy makers, and the public about hepatitis C;
  - 3. Collection and analysis of hepatitis C data and dissemination of findings to stakeholders;
  - 4. Support for hepatitis C-related research; and
  - 5. Reduction in the number of new hepatitis C infections and hepatitis C-related deaths."
- Assess the internal and external environment in light of what you wish to accomplish. This involves identifying what opportunities and barriers the group may face in accomplishing its mission.

- 1. Identify external environment challenges, barriers, and strengths.

  This would include, for example, an understanding of the current political climate in your jurisdiction and what effect this will have on identified goals.
- 2. Identify internal strengths. This involves cataloging key strengths that work group members and their respective organizations bring to viral hepatitis integration. This would include, for example, an exhaustive listing of all the services available for hepatitis C prevention and care across the state, in addition to other resources that individuals may bring, such as access to policy makers, skills in research design and evaluation, and entrée to affected populations. Internal strengths may also include the capacity that the individual organizations and the work group have to address challenges.
- 3. Identify internal challenges or obstacles. This involves looking at the strengths and resources available and assessing what needs are not being met, and how the work group is challenged to meet those needs. Some challenges could include the lack of a coordinated system for reporting hepatitis C infection across the state, and/or the lack of funding to develop training and education for health care professionals.
- Identify goals and objectives and prioritize which goals are most important. As a group, decide which goals can feasibly be achieved in the defined time frame, and develop the objectives needed to meet those goals. Remember to keep your objectives SMART: specific, measurable, action-oriented, realistic, and timebound. <sup>4</sup>
- Develop action steps to meet the identified goals and objectives. The following is an example of a goal, objective, and action steps from California's strategic plan:

Goal: Significantly decrease the number of people newly infected with hepatitis C using the most effective primary prevention strategies.

Objective: Develop and implement a targeted statewide media campaign to increase awareness and provide risk reduction information about hepatitis C. The campaign will be aimed at the general public, identifies high-risk populations, and other populations that may be underserved because of language, culture, or other barriers.

Action steps: During year one, the CDHS (contingent on funds) should:

- 1. Convene a group to advise the Department on the planning and implementation of a targeted statewide media campaign.
- 2. Develop targeted social marketing, public relations, and advertising strategies using the best epidemiological information available, and issue requests for proposals to implement them.
- 3. During year one, advocacy groups will:

  Take the lead in the development of the appropriate policy and legislation to support a hepatitis C media campaign.

# Securing Legislation and/or Funding

ntegrating viral hepatitis into existing HIV and STD programs takes the support and careful planning of stakeholders invested in the issue. Viral hepatitis programs can be integrated for less money than they would cost to stand alone, but in order to be sustainable,

money is necessary to fund staff and program operations. Resources to fund programs can be found through private and government sources.

# recommendations from jurisdictions

- Contact pharmaceutical companies. Many companies have small amounts of money that they can provide with no strings attached.
- Keep abreast of CDC program announcements.
- Utilize the diversity of the populations affected by viral hepatitis to appeal to a wide range of funding agencies.
- Propose using funds to expand viral hepatitis activities into existing successful programs and infrastructures.
- Consider collaborating with your local Veterans Hospital.

# WHY IS SECURING FUNDING AND LEGISLATION TO SUPPORT VIRAL HEPATITIS INTEGRATION ACTIVITIES IMPORTANT?

Integrating aspects of viral hepatitis programs into existing HIV and STD programs may be achieved with limited funds, but obtaining additional funding to support the development of a viral hepatitis infrastructure will be necessary. Identifying stakeholders, developing a work group, elucidating the needs around viral hepatitis, and developing a plan to address these needs are all key tactics in a strategy to secure legislation and/or funding for integration activities.

### WHO HAS PROVIDED FUNDING TO JURISDICTIONS FOR VIRAL HEPATITIS?

Private and government sources have provided funding to support viral hepatitis

activities. Funding from the federal government is largely

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provided through the Centers for Disease Control and Prevention (CDC), while state governments have appropriated funds and/or mandated viral hepatitis programs through state legislation. Although private sources often provide less substantial awards than government sources, some jurisdictions have used private funds to augment other funds or to fund small viral hepatitis planning activities. Please see Appendix A for a more detailed description on viral hepatitis funding.

# WHAT JURISDICTIONS HAVE PASSED VIRAL HEPATITIS LEGISLATION?

Several states have passed laws or received appropriations from their state legislatures to address viral hepatitis, particularly hepatitis C. Hepatitis C drew national attention and concern from policy makers and their constituents after the Surgeon General initiated national "look back" efforts in

# recommendations from jurisdictions

- Utilize stakeholders who have access to policy makers.
- Utilize a diverse group of constituents to share their personal stories about viral hepatitis. Veterans and individuals that were infected with hepatitis C through contaminated blood are often more attractive to policy makers than other high-risk populations.
- Integrate viral hepatitis into existing programs and infrastructures that have demonstrated success, such as HIV/AIDS programs.

1998. which was а campaign to notify the recipients of blood from donors infected with hepatitis C. Appendix B highlights examples from the following five states who have received funding from their state legislatures to address viral hepatitis: Arizona, California, Colorado. Florida and Texas. Although their processes and outcomes differ, the five states share some common factors that helped to advance hepatitis C legislation. These factors include awareness initiation of the issue by either the community, health department, or policy makers; the development of

coalitions to secure and maintain support for the legislation; and an understanding of each state's legislative process.

# Action Steps

# securing funding and legislation for viral hepatitis

## funding

- Research opportunities for funding. Consider foundations or pharmaceutical companies that may have viral hepatitis or public health initiatives. Some companies include Schering Plough: http://www.schering-plough.com; GlaxoSmithkline: http://corp.gsk.com/community/gcp\_criteria.htm; or search for foundations offering funding: http://www.fdncenter.org.
- Think creatively about how to frame your project. Consider all the diverse populations and issues involved and search for funding agencies with an interest in those populations/issues. For example, consider approaching funding agencies that provide money to veterans, to hemophiliacs, to substance abusers, to women, or to communities of color. Consider how your project fits into an agency's philanthropic mission, and approach the agency from their perspective.
- Demonstrate the need for money to address viral hepatitis by presenting epidemiological data and programmatic data from your state to potential funding agencies. A strategic plan, needs assessment, or white paper are also valuable documents that help illustrate the problem.
- Present a detailed plan on how you propose to use the money, and how the project will be sustainable.

### legislation

- Contact local HIV and hepatitis advocacy groups who are interested in getting involved.
- Present a state legislator with a plan that can be used to draft legislation.

## References

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- <sup>4</sup> Singleton, RA, Straits, BC. *Approaches to Social Research*. New York: Oxford University Press; 1999.
- <sup>5</sup> Carey, James W.; Wenzel, Patrick H.; Reilly, Cindy; Sheridan, John; Steinberg, Jill M.; and Harbison, Katherine (2000). *CDC EZ-Text: Software for Collection, Management and Analysis of Semi-structured Qualitative Databases* (Version 3.06C, released February 7, 2000). Atlanta, GA: Developed by Conwal, Inc. and CESSI, Inc. for the Centers for Disease Control and Prevention. Software distributed at: http://www.cdc.gov/hiv/software/ez-text.htm.
- <sup>6</sup> Hepatitis C: An Emerging Health Concern for Texans, Texas Department of Health, Infectious Disease Epidemiology and Surveillance Division, 1998.

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- <sup>7</sup> The Hepatitis C Strategic Plan: A collaborative approach to the emerging epidemic in California. California Department of Health and Human Services, Office of AIDS Available on the world wide web at: http://www.dhs.ca.gov/ps/dcdc/pdf/Hepatitis%20C%20Strate gic%20Plan%20-%0d%202001.pdf.
- <sup>8</sup> Allison, M., Kaye, J. (1997). Strategic planning for non-profit organizations: A practical guide and workbook. New York: The Support Center for Strategic Planning.
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# Appendix A

#### Private sources of Funding

Several jurisdictions obtained "seed money" from pharmaceutical companies to support viral hepatitis projects. Maine received funding from Schering Oncology Biotech, Glaxo Smithkline Beecham, and Merck & Company to conduct a needs assessment. Rhode Island partnered with Schering Plough to survey state medical providers about hepatitis C and to fund a nurse who provided case coordination to clients infected with hepatitis C. Florida partnered with Home Access testing kits to develop a statewide hepatitis hotline which provides free testing kits to eligible callers.

#### STATE SOURCES FOR FUNDING

Several jurisdictions have received appropriations from their State Legislature to fund viral hepatitis activities. Appendix B provides information on Arizona, California, Colorado, Florida and Texas.

#### FEDERAL SOURCES OF FUNDING

# Centers for Disease Control and Prevention (CDC) The Division of Viral Hepatitis (DVH)

• The Division of Viral Hepatitis in the National Center for Infectious Disease (NCID) at CDC provided a total of \$6,888,218 to support viral hepatitis activities in FY 2001. \$2,358,484 of that total was awarded to 15 state and local health departments under program announcement 00046: "Integration of Viral Hepatitis Prevention Services Into Existing Prevention Programs." This cooperative agreement is to develop strategies and guidance for integrating recommended viral hepatitis prevention and control services for persons at high risk for infection in settings that proThe Integration of Viral Hepatitis into HIV/AIDS Programs: Appendix A

vide public health services, and to improve public health service delivery by integrating viral hepatitis prevention services to reach persons at high risk of disease. The application was competitive and all state and territory health departments, the six directly funded cities, and Baltimore, Maryland were eligible to apply. Funding was distributed to 15 jurisdictions for a twelve-month budget period within a project period of up to three years; the average award was \$200,000.

- DVH also disbursed \$2,000,0000 to thirty-four jurisdictions to support hepatitis C coordinators. The hepatitis C coordinator serves as a liaison with other public health programs such as HIV/STD, immunizations, substance abuse, and corrections. Goals of the coordinator position include helping to successfully integrate hepatitis C into existing prevention programs, ensuring medical referrals for hepatitis C infected individuals, supporting hepatitis C surveillance efforts, ensuring laboratory capabilities for hepatitis C testing, conducting trainings for health professionals and organizations on hepatitis C, and evaluating the effectiveness of hepatitis C prevention activities. These awards are made through the Epidemiology and Laboratory Capacity (ELC) cooperative agreement program; Hepatitis Prevention and Control is one of six programs funded under the ELC cooperative agreement. The application is competitive, funding proposals range between \$55,000 to \$110,000, and project periods are up to three years.
- The ELC cooperative agreement also provided \$500,000 to seven hepatitis C surveillance projects, five of which are in different locations from states with hepatitis C coordinators. The purpose of these grants is to assist grantees in the development, implementation, and evaluation of surveillance systems to identify persons with chronic hepatitis B virus and hepatitis C virus infection.
- DVH also provided \$200,000 to the National STD/HIV hotline and STD/HIV Prevention and Training Center Network, and \$250,000 to state and local health departments for special HIV integration efforts.
- DVH awarded a total of \$1,433,000 to 10 national and regional non-profit organizations under program

announcement 00047: "A Cooperative Agreement to Test, Disseminate and Evaluate (A) Educational Materials and Messages, and (B) Training Programs Concerning Prevention and Control of Viral Hepatitis." The application was competitive, the average award is \$143,000, and the project period is three years.

DVH also awarded the National Commission on Health Care (NCCHC) \$146,734 to help support the development of curricula on viral hepatitis education to correctional officers.

# Centers for Disease Control and Prevention (CDC) The National Immunization Program (NIP)

 Other CDC funding to support viral hepatitis activities is given through the National Immunization Program (NIP); NIP provides funding to every state and territory for a hepatitis B coordinator. The hepatitis B coordinator ensures that pregnant women with hepatitis B infection are identified so that transmission to their baby is prevented, and promotes hepatitis B vaccination to all children and all groups that are at high-risk of infection. NIP also supplies hepatitis A and B vaccine to states through the Vaccines for Children Program (VFC). VFC is an entitlement program that provides vaccine free of charge to VFC-eligible children through public and private providers. VFC-eligible children include: children under 18 who are eligible for Medicaid; children without health insurance: Native American and Alaskan Native children; and children with health insurance that does not cover immunizations, provided that they seek care at a Federally Qualified Health Center. In addition, NIP provides hepatitis A and B vaccine to states under the 317 program; this program is authorized under Section 317 of the Public Service Act. NIP allocates 317 funds indirectly to jurisdictions by providing them with an account at CDC through which they can purchase vaccine against.

# Department of Veterans Affairs (V\A) Veterans Health Administration (VHA)

 The Department of Veterans Affairs (VA) is another federal source that supports viral hepatitis. In FY The Integration of Viral Hepatitis into HIV/AIDS Programs:

2001 the VA appropriated nearly \$152 million for hepatitis C programs and services. These dollars were not earmarked for any specific hepatitis C activity such as counseling, testing, or treatment; VA facilities receive the funding based on each facility's hepatitis C workload under a allocation system called Veterans Equitable Resource Allocation (VERA).

# Appendix B

#### **A**RIZONA

In 1997 hepatitis C became a reportable disease in Arizona, and a hepatitis C surveillance system at the Arizona Department of Health (ADH) was not yet in place to manage the lab reports that began to be submitted. An epidemiologist who worked at ADH was very interested in increasing awareness of hepatitis C and increasing the capacity of the public health system to address hepatitis C, and he shared his interests with an Arizona state legislator who was also a close friend. Also at this time another Arizona state legislator began receiving calls from constituents infected with hepatitis C. The result of this heightened awareness of hepatitis C among state legislators was that in 1999, Rep. Gerard (R) proposed a strike-everything amendment to HB 2482, which allocated \$350,000 from an existing allocation from the tobacco tax and health care fund for operational costs of the Arizona State Immunization Information System. The strike-everything amendment read as follows: "The strike-everything amendment provides funding from an existing allocation from the tobacco tax and health care fund to establish a statewide surveillance and targeted education program for persons with HCV." The \$350,000 allocation was for FY's 1999-2000 and 2000-2001.

The success of this allocation was largely due to the efforts of opinion leaders in ADH who had access to influential policy makers; the public was not involved in lobbying the legislature for funding. However, in 2000 the bill came before the legislature for refunding and by this time, an AIDS community and hepatitis C constituency had evolved around hepatitis C issues, and the group

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lobbied the legislature to refund the bill. Their actions combined with ADH's request for refunding resulted in continued funding of the program at \$350,000.

#### **C**ALIFORNIA

In 1998 the California state legislature passed SB 694, the Hepatitis C Education, Screening, and Treatment Act, sponsored by Representative Polanco (D- Los Angeles). Rep. Polanco serves as the chairman of the prison construction and operations joint committee. Survey research in California's correctional facilities was emerging at this time that estimated a high prevalence of hepatitis C among California's inmates.

In response to this information, Rep. Polanco drafted SB 694, and contacted the American Liver Foundation's (ALF) San Diego chapter to help garner support from community organizations across the state. The ALF-San Diego immediately began a letter writing campaign to influence legislators to support the bill, and approximately thirty-three organizations which included universities, agencies, health professional associations, pharmaceutical companies signed on in support of the bill. This bill appropriated no funds for hepatitis C, but declared the intention of the Legislature "to study the adequacy of the health care delivery system as it pertains to hepatitis C." The bill also required the State Department of Health Services to make available protocols and guidelines developed by the National Institutes of Health and California legislative advisory committees on hepatitis C for education for physicians and health professionals and training community service providers. This bill specifically states that nothing in the bill should be construed to require the department to develop or produce any protocol, guideline, or proposal.

SB 694 laid the foundation for SB 1256, which was signed into law in September of 2000. This bill, sponsored by Rep. Polanco, builds on SB 1256 and allocates \$1.1 million to fund hepatitis C education, outreach, and screening. This bill earmarks half of the appropriated funds to educate, screen, and treat veterans for hepatitis C. The bill directs the Director of Health Services to develop and implement a public education and outreach program to raise awareness of hepatitis C among high-risk populations, health care professionals, and the general public; to include information

on co-infection with HIV or hemophilia with hepatitis C in all professional training and care and treatment programs under the department's jurisdiction; to develop a program to work with the Department of Corrections to identify and provide counseling and treatment to inmates infected with hepatitis C; to advocate local public health officials to provide hepatitis C screening for the uninsured; and to include hepatitis C counseling, education, and testing into local state-funded programs that address HIV, STDs, and TB.

#### **C**OLORADO

In 1999, the Colorado state legislature passed HB 99-1118: "An Act concerning implementation of a public health program to address hepatitis C, and making an appropriation therefor." Rep. Johnson (R- Larimer Weld) was the lead sponsor in the House and Rep. Teck (R-Mesa) was the lead sponsor in the Senate. Hep C Connection, a non-profit hepatitis C organization in Denver, approached Rep. Johnson about sponsoring the bill. The bill faced very little opposition in the State Legislature. The bill authorizes the executive director of the department of public health and environment to create a hepatitis C education and screening program. It directs that the program include the coordination of local public health officials, health care professionals, public institutions, and community organizations to identify high-risk populations, to assist in the implementation of a screening process, and to provide information on referral services or assist in finding treatment for persons with hepatitis C infection. This bill also requires the program to provide public education and outreach services to raise the public's awareness and understanding about hepatitis C.

The bill states that the program may be implemented in stages, based on funding available. It further allows the director of the department of public health and environment to implement a system to investigate, collect, analyze, and report data on hepatitis C, contingent on resources available.

This bill appropriated \$200,000 from the general fund to the department of public health and environment for implementation of the act. The Integration of Viral Hepatitis into HIV/AIDS Programs:

#### FLORIDA

In 1998, the Surgeon General wrote a national letter to notify transfusion recipients of the potential risk of having received blood from donors infected with hepatitis C. At that time, the Florida Department of Health (FDOH) began to plan for the needs hepatitis C would present to the public health In addition to internal planning, the FDOH sponsored two "Hepatitis Summits." Participants invited to the summits included partners such as substance abuse agencies, individuals working in immunization programs, community based organizations, the American Liver Foundation, Hep C Alert, hepatitis activists, and veterans organizations. At the same time as the summits, several private corporations were meeting with the legislature to discuss viral hepatitis funding. In 1999, the Florida state legislature appropriated \$2.5 million from a general legislative appropriation in FY 1999-2000 to establish the Florida Hepatitis and Liver Failure Prevention and Control Program.

In FY 2000-2001, the Conference Report on House Bill 2145, General Appropriations Act, Specific Appropriation 529 mandated the development of a statewide hepatitis hotline to provide information and counseling related to hepatitis and the utilization of FDA approved at-home testing kits. The Florida hepatitis A program was also established by CS/SB 2034, Section 36. Section 381.00325, Florida Statutes, and reads: "The Department of Health shall develop a Hepatitis A awareness program. This program shall include information regarding the appropriate education of the public and information regarding the availability of Hepatitis A vaccine. The department shall work with private businesses and associations in developing the program and disseminating the information."

The Florida Legislature continues to provide funding for the Hepatitis Program from the general appropriations fund; \$3.5 million was appropriated in FY 2000-2001, and again in FY 2001-2002.

#### **TEXAS**

In 1998, the Texas Department of Health (TDH) published a white paper on hepatitis C entitled, "Hepatitis C: An Emerging Health Concern for Texans." This paper outlined information about hepatitis C as a growing health concern, proposed health solutions, and estimated the costs of

comprehensively addressing the issue. The white paper was given to Rep. Glen Maxey (D-Austin), a member of the Texas House Committee on Public Health, who was receiving constituent calls regarding hepatitis C. Rep. Maxey used information from the white paper to draft House Bill (HB) 1652, the Education and Prevention Program for Hepatitis C. HB 1652 was passed and signed into law in May 1999.

This bill mandated TDH to conduct seroprevalence studies to determine the current and future impact of hepatitis C on the state; conduct health education, public education, and community outreach activities about the risk factors and the value of early detection; provide training to public health clinic staff; identify to health care providers and employers the benefits of disease awareness and prevention; and develop a prevention program. The bill further required that TDH establish voluntary hepatitis C counseling and testing sites within each public health region. The bill also required TDH to develop and offer a training course for persons providing hepatitis C counseling. The 76th Legislature appropriated approximately \$3 million for the biennium to implement these mandates.

In 2001, the 77th Legislature passed SB 338 which required that TDH develop a statewide plan for the prevention and treatment of hepatitis C. The state plan must include strategies for prevention and treatment of hepatitis C in specific demographic groups that are disproportionately affected by hepatitis C, including persons infected with HIV, veterans, racial or ethnic minorities that suffer a higher incidence of hepatitis C, and persons who engage in high risk behavior, such as IV drug use. The bill requires TDH to seek the input of the public to develop the plan. The plan must be updated every two years. TDH is hiring a state planner to complete this mandate.

SB 338 also required registered nurses to receive no less than two hours of continuing education related to hepatitis C and applies to license holders who renew on or after June 1, 2002. The bill also required the Texas Board of Nurse Examiners to recognize, prepare, or administer a hepatitis C training component for use in continuing education for license holders.

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The 77th Legislature also passed HB 767 to require the Texas Commission on Alcohol and Drug Abuse to include six hours of training during each two-year licensing period relating to HIV, hepatitis C, and STDs in continuing education for chemical dependency counselors.

During the 77th Legislature, HB 768 was also passed which changed the name of the HIV/AIDS Interagency Coordinating Council to the Interagency Coordinating Council for HIV and Hepatitis. The bill was designed to facilitate communication between agencies and associations education. improve awareness. and strategic communication across these organizations regarding hepatitis. Each state agency on the council must send a representative to at least three of the quarterly meetings each year. The council is also required to provide an opportunity for public input. This bill requires the council to file a report containing policy recommendations that include prevention and delivery of hepatitis-related health services no later than September 1 of each even-numbered year with the legislature and the governor.

# 2

# Viral Hepatitis in the Correctional Setting

# Viral Hepatitis in the Correctional Setting: The Role of State, Territorial, and Local HIV/AIDS Programs

s the magnitude of the nation's viral hepatitis epidemic is more widely recognized, the resources of state, territorial, and local health department HIV/AIDS programs are increasingly focused on addressing this emergent public health problem, due to similar populations affected and similar routes of transmission as HIV. Among the most challenging settings in which to address both HIV and viral hepatitis are in city and county jails and in state and federal prisons. The logic for such integration is sound both organizationally and from the perspective of public health, considering that HIV and hepatitis B and C are bloodborne pathogens that are transmitted in similar ways and can be prevented by common interventions; similarly, hepatitis A, B, and C impact many of the same populations as HIV. The existence of a well-developed HIV/AIDS/STD infrastructure presents a prime opportunity to address viral hepatitis efficiently and effectively. Integration fosters an approach that maximizes the health of the public as well as of individuals by proactively offering testing, counseling, referral, and other services to high-risk individuals as well as conducting surveillance and other core public health functions.

Indeed, departments of corrections have very different mandates and different "organizational cultures" than departments of health, sometimes leading to inter-departmental conflicts and misunderstandings. Similarly, policies and programs used to prevent and control HIV/AIDS and viral hepatitis in the general population may not translate to, or may simply not be allowed in, a correctional setting. This often requires significant planning, negotiation,

policy development and/or adaptation and modification. However, the highly structured environment of a correctional system also makes inmates a readily accessible population, which can in some cases actually facilitate application of public health interventions.

Whatever the difficulties involved in serving the incarcerated, it is imperative that they be overcome because in reality, the gap between public health and public corrections is quite small – the incarcerated population presents health problems related to infectious disease as well as mental health, substance abuse and, frequently, a lifetime of being medically underserved. In particular, this is a population at very high risk for both HIV and viral hepatitis. Epidemiological evidence about prisoners indicates that between one and two thirds report a history of injecting drug use before incarceration. There also is evidence of continued drug-using, tattooing and

# ...the gap between public rectional settings. health and public corrections is has quite small...

sexual risk behavior in cor-Since 1997 there been eight-fold increase in the number of people

incarcerated for drug-related offenses, leading to the likelihood of a significant increase of blood borne diseases in the correctional setting. Indeed, one 1994 study of entrants into California prisons reported an HCV seroprevalence rate of 41.8% compared with 1.8% in the US general population<sup>1</sup>.

With 400,000 prisoners released annually back into the community, addressing viral hepatitis among the incarcerated also has broader community-based public health implications. The opportunity to screen, test, vaccinate, and treat high-risk individuals while they are in the controlled environment of a correctional facility is good policy for both individuals and communities.

This document provides a broad overview of the issues concerning viral hepatitis among the correctional population, profiles the efforts of several jurisdictions, and provides recommendations for HIV/AIDS programs.

## **CORRECTIONS: KEY TERMS, FACTS, AND CONCEPTS**

The correctional system may be unfamiliar to many who work in public health. Below are a few key terms, facts, and concepts from the U.S. Bureau of Justice Statistics<sup>2</sup> and the Office of Juvenile Justice and Delinquency Prevention<sup>3</sup>.

- **Jails** are locally operated correctional facilities that confine persons before and/or after adjudication. Inmates sentenced to jail usually have a sentence of one year or less, although this can vary by jurisdiction. Jails also incarcerate persons who are in the midst of a criminal justice procedure or being transferred between facilities.
- **Prisons** are operated either by a state or by the federal government, and they confine only those individuals who have been sentenced to one year or more of incarceration. Generally, people sentenced to prisons have been convicted of a felony offense. The use of privately operated prison facilities is increasing. At mid-year 2001, private facilities held 6.8% of all State and Federal inmates, compared to 6.5% at year end 2000.
- **Juvenile facilities** are used to incarcerate individuals under age 18. The facilities vary in organization; some are similar to prisons while others are designed to resemble a home. There are more than two times as many privately operated juvenile facilities than publicly operated facilities, although private facilities hold less than half as many juveniles as public facilities.
- At the end of the year 2000, 6.5 million people were on probation, in jail or prison, or on parole. This figure represented 3.1% of all U.S. adult residents or one in every 32 adults. The incarceration rate has more than tripled since 1980.
- At mid-year 2001, there were 1.4 million prison inmates, fewer than 100,000 of whom were women and 1.25 million of whom were under state jurisdiction. Jails held or supervised approximately 700,000 persons. Nearly 4.6 million people were on probation or parole at the end of 2000.
- At mid-year 2001, there were 4,848 sentenced black male inmates per 100,000 black males in the U.S.; the comparable statistics were 1,688 for Hispanics and 705 for whites.
- According to The Census of Juveniles in Residential Placement (CJRP) conducted in 1997, on one day in this country 105,790 juveniles were held in juvenile facilities. Sixty-seven percent of juveniles committed to public facilities were minorities and 55% of juveniles held in private facilities were minorities. The one-day count of youth under the age of 18 held in local adult jails was 9,100.

## Understanding the Structure of Health Care Services in the Correctional Setting

ecause there is an enormous degree of decentralization and institutional autonomy among departments of corrections, it is difficult to make generalizations about structures of health care services.

However, a few general patterns have been observed.

# How is health care structured in the correctional setting?

The National Commission on Correctional Health Care (NCCHC) surveyed the departments of corrections in all states, the District of Columbia, the federal bureau of prisons, and the 30 largest jail systems in the country. In 1999, after extensive follow up, responses were received from 54% of prison systems and 27% of the jails and the results were published in the report *Correctional Health Care.*<sup>4</sup> It is important to note this low response rate; the below statistics are not representative of state departments of corrections but rather provide a snapshot of the 28 responding prison systems.

The majority (21/28) of the responding prison systems operated health services with outside staff, often with

- national for-profit firms. Over one-third (11/28) used a mixed model of outside contractors and DOC staff. Similar numbers (9/28) used only outside contractors. The remainder (7/28) used only their own employees. Nearly all had some other professional services contracts, such as with laboratories or pharmacies.
- "These were DC, NY, UT, MT, NE, OR and WA

Each of these models has strengths and weaknesses, but "with respect to correctional health care services, the

<sup>1</sup> These were AZ, FL, NC, SC, MI, MN, OK, TN, VA, OH, WI, and the federal Bureau of Prisons.

These were ID, KS, and MA. MD, MO, PA, SD, TX, and VT.

basic legal issue is whether the care provided is adequate regardless of who provides it." The report also states that DOC staff should have "line authority" over health personnel and recommended that "the health services program includes medical, dental, and mental health care under the same organizational umbrella."

#### How can a jurisdiction's emphasis on CORRECTIONAL HEALTH CARE BE ASCERTAINED?

Four key factors which can be used to ascertain from the outside the degree of emphasis placed on health care within a given prison system are identified in Correctional Health Care. These four factors can be combined to provide a rough estimate of how high a priority health care is within a prison system, although it is only a rough and imprecise indicator.

#### Organizational Level

The first is to determine the organizational level at which health care is placed: is it in its own separate division, is it a section within a division, or is it simply a group within a sec-

"The location of the health (DOC) is often a reflection of the services program within the (DOC) is often a reflection of the perceived importance of health care in relation to the DOCs department's total mission."

tion? "The location of the health services program within the perceived importance of health care in relation to the department's total mission." As might be expected, higher organizational placement suggests greater prioritization. "Some organizationally place health services with programs such as food services, religious activities, and library services, but this is not recommended.

Establishing the importance of health care in a DOC's total mission...argues for a separate division with direct access to the head of the DOC."iv

#### Presence of a Health Services Director

The second factor is to ascertain whether or not there is a system-wide health services director (HSD), which the report indicates is crucially important. "Every state DOC - no matter how small – and all large jail systems should have at least one full-time employee who is responsible for health services system-wide." This individual should oversee health care delivery, set policies, manage budgets, and monitor outside contractors.

#### **Reporting Structure**

The third factor is to determine to whom the health services director reports: directly to the head of the department of corrections (first level), to a deputy (second level) or to an assistant (third level). "The HSD should report directly to the head of the department of corrections. Health care is one of the most crucial and most costly services provided to inmates."

#### **Credentials of Health Services Director**

The fourth factor is to examine the professional credentials of the health services director. Is that individual a physician, another clinician (e.g., a physician's assistant, a registered nurse, or a psychologist), a health administrator, or a corrections administrator? "The credentials of the person serving as the HSD are as important as the level to which the posi-

tion reports." The position of HSD requires both clinical and administrative skills, the ideal is a physician with an extensive administrative background. Another model that could work well, however, is a physician-administrator team.

- Among survey respondents, separate divisions were reported by eight DOCs (DC, NY, UT, AZ, FL, NC, SC, and the federal Bureau of Prisons.) Separate sections were reported by seven DOCs (MT, NE, MI, MN. OK, TN, and VA). Separate groups were reported by OR, WA, OH, and WI.
- First-level reporting occurred in AZ, DC, FL, KS, NC, NY, SC, TX, and UT. Second level reporting occurred in ID, MA, MD, MI, MN, MO, MT, NE, OK, PA, TN, VA, and VT. Third level reporting occurred in OH, OR, WA, WI.
- vi Physicians were the HSDs in AZ, DC, FL, MD, MT, NC, NY, OK, and TX. Other clinicians were the HSDs in ID, VT, and WI. A health administrator was the HSD in MI, MN, MO, NE, OH, OR, SC, TN, VA, and WA. A corrections administrator was HSD in KS, MA, PA, SD, UT, and the federal Bureau of Prisons.

#### **HCV** AMONG THE CORRECTIONAL POPULATION: KEY FACTS

The Association of State and Territorial Health Officials (ASTHO), of which NASTAD is an affiliate, produced a study in November 2000 entitled *Hepatitis C & Incarcerated Populations: The Next Wave for Correctional Health Initiatives* (www.astho.org/infecious/hivaids.html#documents). Some of its major points included:

- "An estimated 1.4 million HCV-infected persons pass through the correctional system each year. Studies of inmate populations in several states found HCV infection rates ranging from 20 to 40 percent, well above the 2 percent infection rate in the general U.S. population."
- "Today, more than 60 percent of HCV infections are attributed to illegal intravenous drug use and that percentage is expected to rise since 9 out of 10 injection drug users may become infected within five years after initiating drug use."
- "This transmission trend is especially problematic in the nation's correctional facili ties. Twenty-five percent of state inmate populations and 14 percent of federal prison ers have histories of injection drug use and 80 percent of all inmates are implicated in crimes linked to drug and alcohol abuse."
- "The majority of incarcerated individuals at high risk for HCV fall into categories where the CDC guidelines recommend testing...Few inmates know their HCV status prior to incarceration because most have poor access to health care, making it unlikely that they have been tested for HCV. Therefore it may make sense for them to be tested in a correctional facility. And while it may be appropriate for corrections to routinely screen inmates for HCV due to the prevalence of injection drug use, most do not."
- "Treatment of an inmate's HCV infection may not be the priority health concern if the inmate presents with multiple morbidities such as co-infection with HIV. Moreover, because treatment options are limited due to severe side effects associated with the treatment, and limited effectiveness of the treatment, correctional doctors may choose not to test when there is no clear course or action for those testing...[and no] financial resources to test inmates for HCV."

# Bridging the DOH-DOC Divide

both though are government agencies, Departments of Health (DoHs) and Departments of Corrections (DoCs) have tremendously different missions, outlooks, and organizational cultures. A major and recurrent theme surfacing from the interviews and research conducted by NASTAD in the development of this module was the difficulty inherent in bridging the divide between these two organizations. "There is a need for constant negotiation," said Julie Subiadur, RN, regarding the work of the Denver Heath and Hospitals Corporation in introducing viral hepatitis testing and vaccination into Denver jails. For instance, the original plans in Denver for simply pulling aside inmates for viral hepatitis screening during their TB testing proved impossible, but they were able at least to set up a sign-up sheet for inmates.

Speaking of HIV/AIDS, but with direct relevance for viral hepatitis as well, the Association of State and Territorial Health Officials (ASTHO) report *Behind the Wall* noted "Traditionally, state public health departments and correctional facilities do not share a common mission. These differences can result in a lack of interagency dialogue, suspicion, and confusion. A definition of public health's mission is likely to encompass themes of community health promotion and disease prevention. Sherriff's departments and state departments of corrections' missions generally include safe custody, public safety, and security."

Still, awareness of and interest in health care issues by DoCs has increased significantly in recent years, according to R. Scott Chavez, MPA, PA-C, vice president of the National Commission on Correctional Health Care. Yet there remain major challenges. "Public health specialists are not trained in corrections. Many don't know where to begin, who to talk to, or what the language or issues are. Many DoHs are struggling because they don't have good relations with DoCs." Similarly, DoC staff generally do not have publichealth training or an orientation towards the provision of social services. Their primary concern is the maintenance of order among a population of convicted offenders, and any diversion from this paramount responsibility may be viewed as compromising security and draining staff resources and funding.

Chavez says that he has found several major issues (see below) that arise when DoHs encounter DoC. Awareness of these concerns can greatly smooth the way for interactions with correctional facility staff.

#### **MAJOR CONSIDERATIONS**

#### A hierarchical organizational culture

DoCs are characterized by a very hierarchical organizational culture. Indeed, although they are not branches of the military, they can nonetheless be characterized as "paramilitary" organizations, says Chavez. They function using many of the same methods as the military, including a strict chain of command with an ordered hierarchy with ranks such as captains and sergeants. (The head of a prison is usually called a warden, while in a jail the head is usually a sheriff – but it is advisable to find the specifics used in each jurisdiction.) Not unlike the military, in which many corrections officers have served, there is an emphasis on appropriate decorum and obedience to authority.

Because corrections staff are also concerned about their own vulnerability to infectious disease, there may be opportunities to enlist them (and perhaps even their unions) as allies, according to Josiah Rich, MD of the Brown University and Miriam Hospital, who has worked extensively in the Rhode Island state prison. In some cases, correctional staff may be motivated to learn more about communicable disease and thus open to educational outreach, and may also be interested in receiving HAV and HBV screening and vaccinations themselves.

#### A strict set of rules

In keeping with their paramilitary orientation, prisons and jails operate under a strict set of rules that individuals do

Recommendations

#### for Collaboration

The ASTHO report *Behind the Wall* provides a number of key findings regarding collaboration in the realm of HIV/AIDS which have great relevance for viral hepatitis as well, including:

- "By assuring that all involved agencies understand the mission and obligations of the other partners, the various agency roles, and accountability, collaboration has a better chance at success."
- "The first stage of collaboration involves dialogue among prospective partners and it can take many forms. Who approaches whom and the types of...activities already taking place in a correctional facility may vary. The initiative for [program development] is most likely to come from departments or divisions within public health or corrections which regularly address and treat infectious disease among this population. In addition, such efforts are also spurred by community advocates and activities of community organizations."
- "Collaborative initiatives ultimately require the support of the policymakers who set the agenda for their respective agencies, targeted funding, dedicated staff, and a commitment to staff education and program sustainability. Discussions between senior officials can lead to cross-agency support of a program, dedication of funding, and staff to implement a full range of services."

not have the authority to alter. "You can't have order and control without rules, so any disruption of the rules upsets people," notes Chavez. Rules could be as simple as, a visitor must walk on the left of a corridor and inmates on the right. If a public health worker were to cross the corridor to speak with an inmate, this would break the established order and would likely be considered inappropriate and unacceptable.

DoH workers or others who come in from the outside and who disregard rules don't get things done effectively. Schedules are also rigid, and it creates additional work and stress on the system to do something as seemingly simple as pulling a prisoner out of an activity for a vaccination or blood draw can cause problems. A "silver lining" of these strict procedures, however, is that they provide opportunities if and when a public health program becomes institutionalized. In Rhode Island, for instance, viral hepatitis vaccines have now become part of the routine during intake, alongside fingerprinting, TB testing, and the taking of a medical history.

#### The need for confidentiality

Despite awareness about the need for patient confidentiality, health care workers routinely talk about

cases with each other in public venues such as hospital hallways or elevators. While this can always be problematic, in the closed environment of a prison, it is critical to refrain from talking openly about an inmate's health, says Chavez. "In jails and prisons, things are overheard and

are repeated, and eventually people piece things together." Even small scraps of information can, cumulatively, compro-

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#### the Experience in Wisconsin

The following approach to overcoming the problem of DoH-DoC "organizational culture clash" has been in use for some time in Wisconsin, according to Marjorie Hurie, Epidemiologist, Wisconsin Hepatitis C Program. Since 1997, the state's Bureau of Communicable Diseases has been holding quarterly meetings with the Department of Corrections and the State Laboratory. These regular meetings have allowed each side to understand the perspective of the others. DoH staffers now understand that while their public health mandate is to serve everyone in the state, the DoC staffers feel so understaffed that they can only focus on those who are incarcerated and are not concerned about what happens after inmates are discharged. This interaction has better enabled DoH staff to understand why health care is just one area of concern among many for DoC staffers, and not always one of high priority.

Another hurdle in Wisconsin has been the engagement of different levels of bureaucracy and the fact that the health care professionals who participate in the joint meetings do not necessarily have the authority to make decisions and implement changes. An added complication is that correctional health care staff report to the DoC rather than the DoH, making it harder to oversee programs. For these reasons, Hurie recommends trying to include someone with such administrative authority as part of the consultative process. But she also noted that health care professionals working in the correctional system have a foot in both worlds, enabling them to help each side understand the other better. These staff members can be cultivated as allies for work inside prisons and jails that is indisputably important but usually also an uphill battle. "Working in the correctional setting takes a lot of persistence," says Hurie," but it can be done."

mise the confidentiality of patients in terms of their HIV or viral hepatitis status or other medical conditions. In Rhode Island, according to Rich, a problem arose when correctional officers sought access to HIV test results, which of course they could not be permitted.

#### Safety and protection

Many who are unfamiliar with correctional facilities have concerns about whether they will be physically safe interacting with people who have been convicted of crimes serious enough to warrant incarceration. But according to Chavez, such concerns are generally unwarranted. "The odds of your being injured in a jail or prison are less than in an emergency room or mental health facility. Assaults on staff are very low. I have been in over 400 jails and prisons in the U.S. and while I am always aware of my surroundings, I feel safer in prison than I do on the streets of Chicago."

Of course, the very same rules and regulations that can frustrate public health workers are also what helps keep them protected. It is important that public health workers entering a correctional facility for the first time understand that they are not being placed in jeopardy. To this end, and also to protect

the jail, the Denver Sheriff's department require security trainings for all public health workers before they are allowed to work in the jail.

Another concern of some is about liability issues, particularly since prisoners as a group are known to file lawsuits. But according to Chavez, recent prison litigation reform legislation, however, has succeeded in diminishing frivolous lawsuits.

## What Key Issues are Raised by Viral Hepatitis in the Correctional Setting?

National Commission ccording the to Correctional Health Care (NCCHC), there are several key issues involving viral hepatitis in the correctional system, which is composed primarily of city and county jails, detention centers, and state and federal prisons. As previously discussed, the principal difference between a jail and a prison is the duration of incarceration, with those in jails serving less than one year and sometimes very short periods. Thus jails often face more difficulties in implementing effective screening and immunization programs that make sure, for example, that the six-month three-shot hepatitis B series is completed, with mechanisms for providing follow-up often very flawed. Prisons generally can establish programs that complete the six-month series, but must often deal with long-term care of hepatitis in prisoners who are incarcerated for long periods of time.

The key issues identified by NCCHC, along with their corresponding recommendations are noted below (the full recommendations can be viewed at www.ncchc.org/statements). NASTAD as well, has commented on these recommendations and has in some cases enhanced program direction. Note that these are goals to strive for and in practice are often subject to significant budgetary, staffing, and other policy and programmatic limitations. In addition to the NCCHC recommendations outlined below, NASTAD also strongly supports expanded substance abuse and mental health treatment within correctional facilities.

#### NCCHC RECOMMENDATIONS:

#### Testing for the incarcerated



#### from NASTAD

- Health departments should seek a more significant role in advising and assisting correctional settings about prevention and treatment of viral hepatitis.
   Where available, studies that document the potential or actual spread of viral hepatitis to the community should be used to establish sound programs for both prevention and care within the correctional institution.
- For viral hepatitis prevention programs within correctional settings to be effective, they must be supported by the availability of both mental health and substance abuse treatment programs.
- Public health disease surveillance for viral hepatitis should be instituted in all correctional settings. Data collected should be available to enhance program planning and policy direction. Reports of disease occurrence, especially acute infections, should be submitted to local public health agencies. Active surveillance should be supported by periodic or routine seroprevalence studies.
- As inmates are paroled or discharged, public health and correctional staff should develop and collaborate in a "discharge planning" system that assures appropriate referral and follow-up for completing immunization series or entering treatment programs within the community as appropriate.
- Where appropriate, integration of viral hepatitis prevention and treatment programs with existing HIV/STD programs should be encouraged.
- Health officials within correctional settings should receive high priority for access to professional education on prevention and treatment of viral hepatitis, HIV and STDs.

All inmates should be screened for HBV and HCV. Those in particular who should be considered high risk and tested include persons with viral hepatitis symptoms, a history of injection drug use, previous jaundice, or who report hepatitis infection should be considered high risk and tested.

#### **Treatment interventions**

Inmates with identified hepatitis should undergo diagnostic studies and be referred to specialists as needed, with treatment initiated and maintained as indicated by a physician.

#### General education

Education about viral hepatitis is recommended for all staff and inmates in jails, prisons, and juvenile confinement facilities. Education should incorporate modes of transmission, prevention, treatment, disease progression, and the availability of HAV and HBV vaccines. Training for staff is also indicated on confidentiality and on universal precautions.

# Counseling for those with viral hepatitis

Inmates with viral hepatitis should receive counseling to encourage treatment and to modify behaviors that could place themselves and others at further risk. Pregnant inmates should receive special counseling about the risk to their babies. Voluntary partner notification should be available to all those who test positive for viral hepatitis.

#### **HBV** vaccination programs

Correctional systems should consider HBV vaccination of at least inmates at high risk for HBV. Vaccinations should be available also for all health care workers and other staff potentially at risk.

#### **Discharge Planning**

Although their legal status may change, the health needs of inmates do not change when they pass beyond the gates of a correctional facility. If anything, most inmates will be returning to environments and lifestyles that may have contributed to their incarceration in the first place. More specifically, there is frequently a need to conduct discharge planning to ensure the completion of the three-dose HBV vaccination as well as continuity of care for those undergoing treatment. The ASTHO Report Behind the Wall provided a number of recommendations for discharge planning for prisoners with HIV/AIDS which are relevant for those with viral hepatitis as well:

- "A model of an integrated continuum of care contains the following key elements: screening and identification of medical and psychosocial problems, psychosocial support services, hospice care, substance abuse treatment, case management, discharge planning, and continuity of care and community linkages."
- "Discharge planning prepares the inmate for release and includes appointments with... specialists in the community [and] making appropriate housing and substance abuse treatment arrangements. Establishing these connections and appointments prior to release is vital because it can be quite difficult to locate an individual following release."
- "Discharge planning not only offers assistance to the soon-to-be released inmate (thus affording a greater chance of proper disease maintenance), but the process itself also provides an opportunity for trust to develop between program staff and the inmate."
- "While facility computer systems attempt to keep track of [releases], inmates are often released with little notice. In jails, the turnaround is so rapid that an inmate can be released before their test results are returned from the lab. A person may also be released at a time of day when public transportation is not available. In Massachusetts county facilities and Michigan state prisons, case management and discharge planning commences the day that an individual enters the facility. This approach is especially valuable in jails, where many individuals may be released within fortyeight hours."

#### Transfer/discharge planning

All viral hepatitis treatment and vaccination records should follow an inmate after discharge or when transferred to another institution. If discharged into the community, follow-up planning is needed for those who have not completed the three-shot vaccination series, and those with active diseases that require provisions for continuity of care.

Additionally, NCCHC has several guidelines for the administrative management of prisoners with HIV that have relevance for those with viral hepatitis infection. NCCHC rejects separate housing for infected prisoners as well as their exclusion from prison programs (unless such separation or exclusion is required for the good of inmate's own health).

**NCCHC** also recommends "the unorthodox conduct of making available to inmates whatever appropriate protective devices can reduce the risk of contagion." This appears to be a euphemism for the distribution of condoms, sterile tattooing equipment, and even sterile syringes (or bleach tablets) even if sex or drug use is illegal among inmates. Another possible, albeit more radical, mode of risk reduction would be the use of methadone maintenance therapy for those facing a relatively short period of incarceration. methadone maintenance therapy might help to keep short-term inmates from using injection equipment with a strong chance of being contaminated with HIV and/or viral hepatitis.

# PROFILE: SAN FRANSISCO INTEGRATING HEPATITIS C TESTING INTO JAIL HEALTH SERVICES

San Francisco Jail Health Services (JHS) is charged with providing "a comprehensive and integrated system of medical, psychiatric, and substance abuse care" to a population of approximately 2200 inmates. including 100-150 arrestees screened per day. The system includes seven jails, six residential facilities and one used for intake. JHS is part of the Community Health Network, the direct care provider for the public health department. JHS comprises medical, psychiatric, TB, STD and HIV components and also works in coordination with numerous health department programs. including STD and TB.

According to JHS Medical Director Joe Goldenson, M.D., San Francisco has long had a very well developed HIV program including health education and risk reduction as well as HIV counseling, testing and early intervention services. JHS also provides a medical intake screening that includes some questions on hepatitis history and on risk factors, providing an opportunity for voluntary HIV testing and limited health education classes. Those with evidence of acute hepatitis are screened and tested. Those who test HIV-positive are generally vaccinated for HAV and HBV if they do not already have immunity. Upon intake, inmates are also provided with hepatitis C risk information and a test request form; this program is currently in a pilot phase and serving limited numbers of prisoners, but plans call for its expansion to all inmates. resources allow, those who request a test receive client-centered multi-infection prevention counseling and a blood draw from JHS nurses. Those testing positive who remain in custody receiving a referral for clinical care and those testing negative are recommended to receive annual re-testing.

The development of a "Protocol for Confidential Hepatitis C Virus (HCV) Testing" reflects many of the challenges and opportunities presented by work in the correctional system. Original plans called for several questions about HCV risk to be included in the standard intake assessment, but this would have increased intake time and required additional staff. In addition, many prisoners proved unwilling to discuss risk behaviors related to illegal drug use, making it hard to accurately identify those at high risk. Thus arose the idea of providing all inmates with printed information and a test request form that can be submitted to request counseling, testing, or vaccination services.

An additional obstacle was the need for rapid laboratory test reporting, which required a switch to the Public Health Department lab and raised logistical issues after limited HCV testing was phased in after January 2002. Among these was the need to train personnel to retrieve electronically transmitted test results and otherwise make use of computer technologies. JHS also plans to conduct hepatitis-specific training for jail medical nurses, whose broad responsibilities rarely offer them the opportunity to specialize. Future plans for expansion of the referral program include outreach through TB and STD programs, preparation of printed materials in languages other than English, and expansion of HBV vaccination to include all vulnerable inmates.

For further detail on the San Francisco Viral Hepatitis Program, including Jail Health Services, visit their extensive Website at www.medepi.org/hepatitis/vhpp.

# PROFILE: HBV VACCINATION IN THE CORRECTIONAL SETTING

One of the most extensive and effective public health interventions possible related to viral hepatitis is the vaccination of at-risk populations. Several jurisdictions have launched vaccination programs for HBV, including the states of Rhode Island and Texas and the City of Chicago. (For additional profiles, see the Website of the Immunization Action Coalition at www.hepprograms.org)

# Rhode Island: Vaccinating Women Inmates

HBV vaccination in Rhode Island has been undertaken as a part of a viral hepatitis integration project at Brown University/The Miriam Hospital in Providence. Rhode Island has a single correctional facility in the state, a combined jail and prison with an average daily population of 3,300 and 16,000 intakes per year. According to Research Assistant Beth Schwartzapfel, the program was funded for three years to evaluate the implementation and preliminary outcomes of an HBV vaccination program. A preliminary analysis determined that it would be cost-effective to vaccinate in prisons, with a savings of \$3,486 per infection averted. In Rhode Island, all inmates, regardless of length of stay, receive an intake including an HIV test, a PPD, a medical history, and a recording of vital signs, to which the idea was presented to add routine HBV vaccination. The addition of the vaccinations and a computerized follow-up process required considerable time to integrate into the existing system, in which nurses were overworked and not always well trained in computer technologies. As of summer 2002, however, staff were in the process of being trained and one-third of newly admitted women were accepting HBV vaccinations, all of whom are eligible to receive the vaccine under the federal "317" immunization program for perinatal prevention. The program is also working with CBOs to follow up for second and third doses after discharge. Pending the availability of funds, the program is to be expanded to include male prisoners.

# Texas: Comprehensive Inmate and Staff Vaccinations

The Texas Department of Criminal Justice has undertaken a mass Hepatitis B Prevention program funded by state general revenue. Since 1996 all correctional facility staff, and since 2000 all offenders

are eligible to receive HBV vaccine free of charge. According to Director of Preventive Medicine Dr. Michael Kelley, there are approximately 145,000 inmates in state prisons and at first about 20,000 doses of HBV vaccine were being administered monthly; that has more recently declined to about 11,000 doses, mostly for newly admitted inmates. The state program also collaborated with the American Correctional Association to produce educational videos to encourage testing and vaccination for inmates, as well as vaccination for correctional officers. After two years of the program, it was found that about 19% of inmates refuse the first dose, while 2% refuse the second. However, 96% of long-term offenders complete the vaccine series once started. The figure is lower for short-term offenders in part because there are not always community resources to which discharged prisoners can be referred for completion of the vaccination series. Screening for HBV and HCV is also available a maximum of every six months.

## Chicago: Vaccination of Adolescents in Juvenile Facilities

In the City of Chicago, funding has been provided through the Division of Adolescent Services in the STD Division to provide vaccine to all adolescents in the correctional system, with vaccine paid for by the federal Vaccines for Children program. According to Chicago HCV Coordinator Corinna Dan, a fulltime Licensed Practical Nurse (LPN) works within the Cook County Juvenile Detention Facility to identify unvaccinated adolescents and apply at least the first dose of HBV vaccine. Because the juvenile facility includes a school run by the Chicago Public Schools system, the LPN is able to work with the school nurse to access vaccination records of all juveniles in the facility. As part of this new program, which at this writing is only a few months old, the LPN is to spend mornings giving vaccinations as part of the standard medical intake (provided that parents or a judge has signed a release form). When the time comes for follow-up shots, afternoons will be spent either providing hepatitis-specific education or sending postcards or making field visits as a reminder that follow-up shots are needed. Since the majority of the adolescents, aged 11 to 19, are not engaging in injection drug use, HBV vaccination plus viral hepatitis risk reduction education is a crucial early intervention.

# Going Forward: Ongoing Funding and Treatment Challenges

s this document has demonstrated, the need to intervene with correctional populations on viral hepatitis issues is clear and compelling and a number of jurisdictions have undertaken pioneering efforts in this area. There are, however, major ongoing and interrelated challenges to providing viral hepatitis services in corrections. Most significantly, funding to implement viral hepatitis prevention and treatment services is inadequate.

#### **FUNDING**

Many jurisdictions have only begun to address the problem of viral hepatitis among general populations, and most programs remain seriously under-funded. Funding programs for populations such as inmates in jail and prison who are often politically and socially stigmatized becomes even more problematic. A few steps, however, may be taken to promote funding for viral hepatitis outreach and prevention for correctional settings:

• Become aware of community advocates and build alliances with community-based agencies. Perhaps because of the stigma associated with injecting drug use, a broad-based grassroots constituency for tackling viral hepatitis has yet to emerge in the U.S. However, there are some community groups concerned with public health in general and with corrections populations in particular. Collaborating and sharing resources can help to stretch scarce resources and also help bolster a community constituency. Community collaborations can also help to promote completion of vaccine series and continuity of care after discharge.

- Work with funding sources, including legislatures and the private sector. Legislative bodies have begun to become more aware of the need to address viral hepatitis. Funding in some jurisdictions has been initiated, without substantial pressure, by an interested legislator. Other jurisdictions have found funding from the private sector, particularly from pharmaceutical companies who produce hepatitis medications.
- Maximize impact by working with other agencies. The populations at risk for viral hepatitis overlap substantially with those at risk for HIV, STDs, substance abuse, and some mental health problems. By coordinating and integrating services, it is possible to avoid duplication and to "piggyback" viral hepatitis outreach through other programs. Viral hepatitis outreach can also help correctional institutions realize that they themselves also have a vested interest in having a population with fewer communicable diseases.

#### **TREATMENT**

If funding for vaccine and for outreach activities is hard to achieve, then the very costly process of treating inmates for active viral hepatitis disease is all the more costly. Costs are so high, in fact, that some jurisdictions may not wish to test at all if there are few or no resources for follow-up.

Such concerns may be exaggerated far out of proportion, however. It is important to realize that comparatively few inmates are likely to actually need treatment even if a comprehensive screening and testing process is in place. Some percentage will refuse testing, some percentage of those tested will test negative, and some percentage of those testing positive will either decline or not need immediate treatment. Many of those who are HCV positive, for instance, will first need a period of observation for liver enzyme levels and only some of those will actually need an ultrasound or liver biopsy. Given the slow progression of HCV, many inmates may well be discharged before they actually need treatment. However, some inmates with HCV will require immediate treatment for hepatitis, and correctional institutions are ethnically and legally bound to provide this treatment. All inmates who test HCV positive can also be counseled about how to reduce further harm, such as by curbing alcohol and drug intake, receiving HAV and HBV vaccinations, and being counseled about how to prevent further transmission of the virus.

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What does research tell us about viral hepatitis

in the correctional setting?

esearch on HBV and HCV in prisons and jails is limited. A search of the comprehensive MEDLINE database conducted by NASTAD in April 2002 revealed fewer than 140 articles published in the Englishlanguage medical literature since 1985. A review of this literature produced several key insights:

# CORRECTIONAL SETTINGS ARE SUSCEPTIBLE TO SIGNIFICANT VIRAL HEPATITIS OUTBREAKS

Because prisons are closed societies, the potential for the explosive growth of a viral hepatitis outbreak is significant. In an outbreak in the U.S. in 2000 reported by CDC, for instance, among a dormitory of 97 men, six had acute HBV infection and one had chronic infection, while 16 had resolved infection. "To control the outbreak, the state's department of corrections offered hepatitis B vaccinations to all susceptible inmates...In addition, acutely and chronically infected inmates were notified of their infection status, received a clinical assessment, and post-exposure prophylaxis was provided to their contacts. The state's department of health and department of corrections collaborated to implement routine hepatitis B vaccination for all inmates in the correctional system."

("Hepatitis B Outbreak in a State Correctional Facility, 2000." MMWR (June 29, 2001) 50 (25) 529-532)

# THE RESPONSE OF CORRECTIONAL SYSTEMS TO HCV VARIES GREATLY

A survey of medical directors of correctional systems in 36 states and the District of Columbia was conducted in 1996 to assess the degree to which prisons screen for and treat HCV. The survey, whose findings may be dated

at this time but remains the most comprehensive of its kind, found that only Colorado reported routine screening. Only California had conducted a systematic seroprevalence study, finding that nearly 40% of inmates were positive for HCV antibodies.

(A. Spaulding et al., (1999) "Hepatitis C in State Correctional Facilities", Preventive Medicine 28 92-100)

## VIRAL HEPATITIS SURVEILLANCE IS NEEDED IN CORRECTIONAL SETTINGS

In a report of a 1993 HBV outbreak in Scotland, investigators stated that "comprehensive surveillance of hepatitis B infection is essential if its epidemiology is to be understood, if clusters of infection are to be recognized swiftly and if appropriate and well targeted public health interventions, including hepatitis B vaccination, are to be conducted to prevent further spread of infection." Another biostatistical study indicated that a definitive study of 3000 prisoners for 10 weeks would be expected to detect the rate of HCV seroconversions.

(S.J. Hutchinson et al. "Hepatitis B outbreak in Glenochil prison during January to June 1993." Epidemology and Infection, (1998) 121, 185-191)

(S.M. Gore and A.G. Bird. "Study size and documentation to detect injection-related hepatitis C in prison." Quarterly Journal of Medicine (1998), 91: 353-357)

## TATTOOING MAY BE A SPECIAL RISK IN THE CORRECTIONAL SETTING

Although there is not clear cut epidemiological evidence that tattooing presents a particularly high risk in correctional settings, there is compelling anecdotal evidence. November 2000 letter, California-based doctors documented the circumstances in which one case of HCV transmission was known to have occurred: "In mid-June 1998, the patient received, in his dormitory, a tattoo (approx. 5 x 3 in) on his right flank. The tattoo device, assembled by inmates, consisted of a small battery-driven electric motor connected to a sharpened guitar string that acted as the tattoo needle. Reportedly, the tattooist poured ball pen ink into a toothpaste cup and drew the ink into a fountain pen-sized barrel attached to the device. The ink flowed along the surface of the guitar string, which punctured the skin as it was driven by the motor. The patient could not tell if the needle had been cleaned if used on other persons. After the tattoo was done, he washed the needle with hot water and returned it to the tattooist."

(Thomas H.F. Tsang et al. "Transmission of Hepatitis C Through Tattooing in a United States Prison" American Journal of Gastroenterology (April 2001), Vol. 96, No 5, 1304-1305)

## UNUSUAL MODES OF TRANSMISSION SHOULD BE CONSIDERED

The unusual circumstances prevailing in prisons and jails may lead to modes of transmission not commonly found in the non-incarcerated population. In a case study of four cases of HCV transmission in an Australian jail, two were associated with injecting drug use. But "in two of the cases, HCV may have been transmitted by means unrelated to drug use. The high prevalence of HCV among those entering prison, together with the strong likelihood of blood-to-blood contact in the prison environment, may increase the chance of HCV transmission by barbers shears, during physical assault, or by other mechanisms." (Paul S. Haber et al. "Transmission of hepatitis C within Australian prisons" MJA (5 July 1999), Vol. 171, 31-33)

## VACCINATION PROGRAMS ARE FEASIBLE IN CORRECTIONAL SETTINGS

A study of a HBV and HIV screening and HBV immunization program in a prison in Marseille, France, produced promising results for promoting immunizations. "The research shows that an HBV immunization programme is feasible in prisons when the staff is given some complementary resources, and that a majority of prisoners (86%) accept an immunization schedule including 3 doses...[I]t is crucial to motivate health professionals about the needs for HBV immunization...Prisoners should be informed about the possibilities to follow up their immunization at an STD clinic or health center outside the prison" in the case of discharge or transfer before the completion of the three-shot series.

(M. Rotily et al. "HBV and HIV screening, and hepatitis B immunization program in the prison of Marseille, France" International Journal of STD & AIDS (1997) 8: 753-759)

## Viral Hepatitis and HIV: **A Primer for Community Planning Groups**

# A Primer for Community Planning Groups

IV prevention community planning groups (CPGs) at the local, regional, and state levels are tasked with working with the health department to develop a comprehensive HIV prevention plan for their area that describes the HIV/AIDS epidemic and recommends how to best meet the prevention needs of populations at risk for HIV infection. Since 1994, the U.S. Centers for Disease Control and Prevention (CDC) has required state and local health departments receiving federal HIV prevention funding to provide leadership and support for HIV prevention community planning. CPGs are asked to make use of epidemiologic profiles, needs assessments, gap analysis, and an inventory of resources in their geographic area to develop a comprehensive HIV prevention plan that identifies which populations are at greatest risk and then recommend priorities for HIV prevention interventions. In determining the needs, CPGs routinely look at disease trends in STDs, incidence of teen pregnancy, prevalence of substance abuse, and other markers that give them information about risk behaviors in targeted populations. As of 2002, community planning involves thousands of individuals as either members of CPGs or their standing and ad hoc committees.

The ever-changing face of the HIV/AIDS epidemic has made the work of HIV CPGs more difficult but also more important than ever. One of the more recent challenges CPGs face is making sense of and helping plan policy about the growing co-epidemics of HIV, STDs, and viral hepatitis.

Viral hepatitis is the name collectively used for the five major recognized types of hepatitis (A, B, C, D, and E). These viruses – known respectively as HAV, HBV, HCV,

### **A Primer for Community Planning Groups**

HDV, and HEV - can cause acute illness as well as chronic infection, posing risks of long-term negative health outcomes including cirrhosis, liver failure, and liver cancer. Often these infections are contracted by the same risk behaviors that result in HIV infection.

Those who have participated in community planning over the past eight years as well as those health departments who actively support it generally agree that community planning has significantly improved the availability of effective, targeted HIV prevention interventions that address the specific needs of populations at highest risk in their communities. Could the same community/stakeholder involvement have a similar impact on the prevention of viral hepatitis? As will be seen, numerous factors play a role in determining whether a CPG chooses to address the prevention of viral hepatitis.

This primer is based on four principles: 1) that stakeholders, in this case community planning members, recognize the efficiency and value of examining the causes of the prevalence of viral hepatitis as a surrogate behavioral marker, which could help in effectively preventing HIV; 2) that preventing viral hepatitis through behavioral based interventions will also positively impact the prevention of HIV; 3) that health departments recognize their leadership role in making community planning for HIV prevention successful, and acknowl-

## This primer is based

edge that this leadership is also critical for the planning and intitiation of viral hepatitis prevention programs; and 4) where input into the planon four principles ning and implementation of viral hepatitis prevention programs is needed or desired, sound public health practice suggests that integrating

> viral hepatitis prevention into HIV prevention planning makes imminent sense and is more efficient.

This primer will largely focus on HAV, HBV, and HCV because they are the most common types of viral hepatitis in the United States. In addition, this primer is being offered to HIV/AIDS programs and their CPGs based on the following facts and assumptions:

 Integration of viral hepatitis prevention into HIV prevention community planning may be appropriate in large cities and/or states where significant spread of HIV is attributable to injection drug use (IDU). Studies have found that after five years of injection, 50 – 80% of IDUs are infected

with HCV¹. Further, 60% of new cases of HCV are attributable to IDU². It is likely that the prevalence of coinfection with HIV and HCV is high in areas with a high prevalence of IDU-related HIV.

- Integration of viral hepatitis prevention into HIV prevention community planning may be helpful in those states/cities where HIV/STD/hepatitis programs are under the same program level administration.
- Integration of viral hepatitis prevention into HIV prevention community planning may be appropriate where active surveillance of HBV and HCV exists and is used (or could be used) as a surrogate marker for disease or behavioral trends for the HIV epidemiologic profile.
- The existence of effective vaccines to prevent HAV and HBV correlates with the disease prevention mission of CPGs.
- Integration of viral hepatitis prevention into HIV prevention community planning is not needed or feasible for all CPGs.

As everyone in the HIV/AIDS field is acutely aware, the challenge of combating HIV is itself an enormous and often overwhelming task. So why, then, should members of CPGs also be concerned about viral hepatitis? A variety of rationales exist that may be appropriate for a given CPG to integrate viral hepatitis into their planning process and make recommendations for combating both HIV and viral hepatitis. Among these are:

### Reaching those at highest risk

Many of the people at highest behavioral risk of viral hepatitis infection are also at highest risk for HIV, including IDUs, health care workers, blood transfusions recipients, men who have sex with men (MSM), and persons with multiple sex partners. One-quarter of HIV-infected persons are also infected with HCV and an estimated 50-90% of persons infected with HIV through IDU are also infected with HCV<sup>3</sup>. A study measuring the incidence and risk factors of persons with acute hepatitis B infection found that of 236 patients interviewed, 84 (35.6%) reported previous incarceration. A total of 110 (46.6%) patients reported one of these two factors, and 21 (8.9%) reported

both<sup>4</sup>. This study clearly illustrates that clients at high risk of viral hepatitis infection access HIV/STD clinics, and that the lack of integrated services results in missed opportunities for prevention and treatment. Integrating viral hepatitis into CPG planning efforts will allow the CPG to make a broader impact on disease transmission in their community.

### Avoiding unnecessary duplication of services

Since modes of transmission and impacted populations overlap, HIV and STD prevention messages can often readily be expanded to incorporate viral hepatitis messages. Similarly, once individuals have entered an HIV or STD counseling and testing site, it makes sense to screen and test individuals at risk for hepatitis C, and vaccinate persons who are at-risk for hepatitis A and B, rather then refer them somewhere else. Providing integrated programs helps avoid creating duplicative or overlapping infrastructures and services that would require the client to visit multiple sites to receive needed services. Further, viral hepatitis requires a strong community and public health response. Planning processes and priority setting will have to be implemented in order to effectively target resources. It may make more sense to broaden an existing planning process rather than create a new process to address a disease that affects many of the same populations as HIV.

### Maximizing existing infrastructure

An extensive network of HIV counseling and testing sites is already in place throughout the country, as are surveillance systems, referral mechanisms, outreach programs, and other services that are necessary for viral hepatitis programs. Re-creating such existing infrastructures would represent an inefficient use of resources. This is also true for human resources. Many CPG members are also affected by viral hepatitis and would take part in viral hepatitis prevention efforts. In order to maximize the use of their time, it may be more effective to combine viral hepatitis with HIV prevention planning.

The integration of viral hepatitis issues into HIV programs also presents some challenges, including:

### Developing capacity

HIV, STDs, and viral hepatitis have many similarities, however, they are not identical. Viral hepatitis is not just one infection, but a family of viruses that includes many different types (e.g. A, B and C) that are very different from each other and require different prevention and treatment messages. Integration of services requires new training and ongoing education to broaden staff knowledge, expertise, and comfort level so they are able to sufficiently educate clients about viral hepatitis and pro-Adding new services usually requires increasing staff sizes as well and building additional infrastructure to handle the demand of increased services. Similarly, for CPGs to effectively address viral hepatitis, education and training is needed to increase their competence so they can make well-informed decisions.

### Securing funding

Although awareness about viral hepatitis is growing, it remains unevenly and frequently inadequately funded.

## Although awareness about integration. viral hepatitis is growing, viral hepatitis can often only be applied to those it remains unevenly and specific frequently inadequately funded.

Further, categorical funding can also be a barrier to Monies earmarked for HIV, STD, or disease gories. For example, it may not be feasible to use money earmarked for HIV to supplement viral hepati-

tis services. The additional costs of hepatitis A and B vaccine and hepatitis C laboratory tests can make integration difficult to achieve, and may frustrate CPGs if they are unable to set priorities to influence viral hepatitis funding.

### Overcoming organizational obstacles

Public health responsibility for viral hepatitis is widely dispersed across multiple programs, including but not limited to infectious disease, HIV/AIDS, STDs, immunization programs, and even environmental health. This can be difficult for CPGs, who may submit recommendations for viral hepatitis to the HIV/AIDS program, who in turn may have little leverage or authority to act upon the recommenda-

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tions. Integration of services will require the cooperation and collaboration of multiple, disparate, public health programs.

Through its viral hepatitis program, NASTAD is committed to assisting state, territorial, and local health departments and other public health entities with meeting these and other challenges. This guide, one of a number of NASTAD viral hepatitis-related projects, is intended to provide members of HIV CPGs with basic background about the types of viral hepatitis and their modes of transmission. While this guide incorporates materials from a number of previously published NASTAD materials, it has been reviewed and adapted to meet the particular needs of HIV prevention community planning groups.

### Viral Hepatitis and its Prevention: the Basic Facts

epatitis A virus (HAV), hepatitis B virus (HBV), hepatitis C virus (HCV), hepatitis D virus (HDV), and hepatitis E virus (HEV) are the five major recognized types of viral hepatitis. Hepatitis literally means inflammation of the liver, and while these five types vary in their potential to cause serious liver damage, all share many of the same symptoms of infection: jaundice (yellowing of eyes), fatigue, abdominal pain, appetite loss, intermittent nausea, and diarrhea.

All five types of viral hepatitis share similarities with HIV and STDs. All are microbes that are generally transmitted through sexual and blood-to-blood contact, all may impact many of the same populations, and all can pose a serious health threat both separately and in interaction with one another. Coinfection with HIV and one or more of the types of viral hepatitis is not uncommon.

HAV, HBV and HCV are the most common types of viral hepatitis in the United States. This primer will focus on the prevalence, risks of transmission, populations affected, and prevention methods for HAV, HBV, and HCV. General descriptions of HDV and HEV will be provided.

#### INCIDENCE AND PREVALENCE

Chart 1 illustrates the disease burden of HAV, HBV, HCV, HIV, and STDs in the United States.

One major difference between HAV and HBV and HCV is that HAV causes acute infection only. In contrast, HBV and HCV can cause chronic infection, which can lead to cirrhosis (scarring of the liver), liver cancer, and liver failure. In the U.S., there are believed to be approximately 150,000 total HAV infections annually, of which about half

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are symptomatic and 100 of which lead to deaths due to fulminant (massive death of liver tissue) hepatitis. One-third of the U.S. population has immunity to HAV, which is evidence of previous infection. While HAV does not lead to chronic infection, the acute stage can be prolonged or can relapse in about 15% of cases.

Outcome	HAV	нву	HCV	HIV	STD*
Chronic Infections New Infections/yr Deaths/yr	~1.2 million ~150,000 100	~2.7 million ~76,000 5,000	~0.8 million ~40,000 8,000	~40,000 18,000	~1.1 million

#### CHART 1:

DISEASE BURDEN OF HAV, HBV, HCV, HIV AND STDS IN THE U.S.

\*Chlamydia (255/100,000 population) and gonorrhea (150/100,000 population) in 2000

Source: Centers for Disease Control and Prevention

There are believed to be about 70,000 new HBV infections per year in the U.S., and approximately 30% of those infected do not experience symptoms. Unlike HAV, about 8,000 HBV infections (6%) become chronic each year, leading to about 5,000 deaths annually from chronic liver disease including primary liver cancer. An estimated 1-1.25 million Americans are chronically infected with HBV, somewhat less than one-half of one-percent of the total population. Ninety percent of infants infected with HBV at birth develop chronic HBV infection, while 6% of persons infected after the age of 5 become chronically infected. Historically HBV prevention programs have focused on identifying pregnant women with HBV infection in order to prevent perinatal transmission.

In comparison to HAV and HBV, new HCV infections are the lowest, with an estimated 38,000 new infections in the U.S. in 1998. Unfortunately, only about 25 to 30 percent of persons infected experienced symptoms; the majority of persons with HCV infection do not experience symptoms and consequently do not learn of their infection. This is why HCV is frequently characterized as the "silent epidemic." About 85% of HCV infections become chronic, leading to liver disease among 70% of infected persons, cirrhosis in about 15% (developed over the course of 20 to 30 years), and death among 5%, a total of some 8,000-10,000 deaths annually. It is estimated that 2.7 million Americans are chronically infected with HCV, and chronic HCV infection is the leading indicator for liver transplantation in the United States.

## ROUTES OF TRANSMISSION AND GROUPS AT HIGH-RISK

Chart 2 illustrates the risks for transmission of HAV, HBV, HCV, and HIV. Due to overlapping routes of transmission,

Risk Factor	HAV	HBV	HCV	HIV
Injection drug use	3-14%	~14%	~60%	31%
MSM	~10%	~15%	1%	47%
Heterosexual partners	~40%	~20%	10%	
Transfusion	rare	rare	past 7- 20%	past 2%
Occupational	NA	past 5-7%	<1%	<<1%
Unknown	50%	30%	10%	9%

CHART 2: RISKS FOR TRANSMISSION OF HAV, HBV, HCV, AND HIV IN THE U.S.

Source: Centers for Disease Control and Prevention

these diseases impact many of the same populations.

HAV is transmitted primarily by oral contact with the feces of infected an

person, or through contaminated food or water. HAV can also be transmitted via blood, but this is believed to occur rarely. Those at highest risk of HAV include individuals who have household or sexual contact with people who have HAV. Increased rates of HAV are also commonly found in certain areas of the world, including some Native American reservations and Alaska Native villages. In particular, all of Latin America, Africa, the Middle East, South Asia, Southeast Asia, and China are regarded as areas of high HAV prevalence. See Appendix C for a map illustrating the prevalence of HAV across the world.

HBV is transmitted in many of the same ways as HIV, although even more easily—it is 100 times more infectious than HIV. HBV can be transmitted sexually via a variety of bodily fluids, especially blood, semen, and vaginal secretions. HBV can also be transmitted perinatally and by sharing drug injection and preparation equipment. The list of those at risk of HBV will seem particularly familiar to people who know HIV/AIDS issues: injecting drug users; sexually active heterosexuals; men who have sex with men; babies born to infected mothers; and healthcare workers. Other populations at increased risk are immigrants (and their children) from regions with high HBV prevalence (see Appendix D for a map of high prevalence areas); those who have household or sexual contact with people with HBV, and people who receive hemodialysis, such as for kidney disease.

HCV is a blood borne virus, so the groups at highest risk are injecting drug users, chronic hemodialysis patients, and health care workers who experience needle stick injuries. Persons for whom routine HCV testing is recommended by the CDC are: those who have ever injected illegal drugs; persons who received blood-clotting concentrates prior to 1987; persons who received blood

transfusions or organ transplants prior to July 1992; children born to HCV-positive women; and health-care, emergency medical, and public safety workers after needle sticks, sharps, or mucosal exposures to HCV-positive blood. It is important to note that because HCV is transmitted so efficiently through needle sharing, any history of needle sharing must be considered a risk factor. As an additional precaution, people with HCV should not donate organs, blood, or semen nor should they share potentially blood-contaminated household items such as razors or toothbrushes.

### **PREVENTION**

One essential component included in HAV and HBV prevention programs is the use of vaccines to prevent infection. Hepatitis A and hepatitis B vaccine are both very safe and highly effective. Immunization against hepatitis A is recommended for household contacts of persons infected with hepatitis A virus; sex partners of persons infected with hepatitis A virus; men who have sex with men; travelers to countries where hepatitis A is common; illicit drug users, both oral and injecting; and persons living in counties, communities or

There are other strategies that can be used to prevent infection with HAV and HBV if vaccine is unavailable or if the client is reluctant to be immunized.

regions of the United States with consistently elevated rates of hepatitis A. Hepatitis A vaccine is

a two-shot series. The second dose should be given six to eighteen months after the first dose. Immune globulin, which is a preparation of antibodies, is also available to prevent infection with HAV. It can be given up to two weeks after exposure to HAV in order to prevent infection, and it can be given prior to exposure to provide short term protection against HAV.

The vaccine for HBV was licensed in 1982 and routine vaccination is recommended for persons from birth to 18 years of age. In 1991 a comprehensive strategy of childhood vaccination was adopted to eliminate HBV infection. Adolescent "catch up" vaccination programs were begun in the mid-1990s. Cases have since dropped significantly due to routine immunization programs, however, increases have been noted among sexually active and drug using individuals. The vaccine, which is given as a series of three shots, provides

protection from HBV (i.e., the development of adequate antibody response) among more than 90% of children, adolescents, and young, healthy adults if the three-dose series is completed. While completion of the three-dose series is ideal and necessary for long-term immunity, even one dose of the vaccine will provide some protection against HBV.

There are other strategies that can be used to prevent infection with HAV and HBV if vaccine is unavailable or if the client is reluctant to be immunized. To prevent HAV infection, safer-sex messages targeted to sexually active individuals, especially men who have sex with men, should warn of the dangers of oral-fecal contact directly through oral-anal sex and indirectly following anal-penile or anal-digital penetration. Since oral-anal and anal-digital contact has not emerged as a source of HIV transmission, it has been de-emphasized in HIV prevention campaigns. In order to minimize transmission of hepatitis A. then, it would be useful both to focus on the value of vaccination for HAV as well as on the need for the use of barrier methods during all anal contact and the need to avoid oral contact with fingers, sex toys, or other objects which may become contaminated with fecal matter during the course of sex activity. It is, further, important to note that oral-fecal contact is especially dangerous for those who are already immunocompromised, since feces can contain a number of parasites that can cause serious gastrointestinal disease. More generally, good hygiene and sanitation might help minimize exposure to HAV.

The basic strategies used to prevent the transmission of HIV through sex and syringe sharing can largely also prevent HBV transmission. HIV prevention messages might do well to include HBV prevention as yet another benefit of safer practices. Further, because of the endemicity of HBV in certain areas of the world, subpopulations from those regions (and their potential sex or syringe-sharing partners) might be targeted for particular emphasis about prevention of HBV.

Unfortunately, there is no vaccine to prevent HCV infection. Although HCV is primarily transmitted through blood-to-blood contact, HIV prevention programs targeted towards IDUs that have achieved a decrease in HIV infection have not achieved a similar decrease in HCV infection. Troubling data has been reported from cities such as

Vancouver, Canada and Sydney, Australia, both of which have comprehensive harm reduction programs with relatively easy access to sterile syringes but have nonetheless continued to see high levels of HCV infection. HCV is more efficiently transmitted than HIV through even a single sharing incident and in order to reduce HCV rates it is necessary to go even beyond current HIV prevention efforts. This prospect faces daunting legal and funding barriers. Among the important messages regarding HCV, however, would be not to share syringes or any paraphernalia such as cookers, cotton or rinse water. It is also critical to increase awareness among IDUs of the risk of HCV transmission through "drug sharing." Drug sharing is a process by which IDUs buy drugs [this applies to tar heroin] with others, prepare the drugs by cooking them, and then use a syringe to accurately measure the drug solution to ensure an even split of the drugs. It is through this process that blood borne viruses such as HCV can be unknowingly transmitted; for example, the use of a contaminated syringe to measure and split the drug solution may transfer a blood borne virus to other injectors.

Finally, because there are several known genotypes (genotype can be determined by looking at the genetic makeup of an individual's virus), or strains, of HCV, it is possible for the same individual to be infected with more than one genotype. HCV genotypes are important because they have a major impact on disease progression and the efficacy of treatments. Therefore, the risk of HCV re-infection must also be emphasized among persons infected with HCV. This risk is often treated as hypothetical in the realm of HIV but has been proven in the case of HCV.

#### **TREATMENT**

Individuals infected with HBV and HCV should be referred for medical evaluation so a doctor can assess the progression of the disease and recommend disease management strategies. Alpha interferon and lamivudine are two drugs licensed for persons with chronic hepatitis B and they are effective in up to 40% of patients. Combination antiviral treatments such as pegylated-interferon and ribivirin are available for people with chronic HCV infection, but these have been effective in only 40-50% of patients. There is a great deal of ongoing research aimed at developing more effective and tolerable treatments, including improving treatment for persons coinfected with HIV. Due to the effects of alcohol on the liver, persons infected with HBV and HCV are recommended to abstain or reduce alcohol intake.

### **HIV/HCV Coinfection**

As previously noted, HCV affects many of the same populations as HIV, and one-quarter of persons infected with HIV are also infected with HCV. The prevalence of HIV/HCV coinfection among individuals who became infected with HIV through IDU is estimated at approximately 60-90%. Although there are limited data on the effects of coinfection, the potential for problems and complications due to infection with these two viruses prompted the U.S. Public Health Service/Infectious Diseases Society of America (USPHS/IDSA) to define HCV as an opportunistic infection in HIV-infected persons in their 1999 Guidelines for the Prevention of Opportunistic Infections in Persons Infected with Immunodeficiency Virus. Studies have found that coinfected persons have higher HCV viral loads than people infected with HCV alone and that HCV disease appears to progress more rapidly in persons with HIV. The data are inconclusive on the effects of HCV on HIV and more research is needed to fully understand the interactions between these two viruses.

U.S. Public Health Service/Infectious Diseases Society of America (USPHS/IDSA) guidelines recommend that all HIV-infected persons should be screened for HCV infection, and CDC recommends that persons infected with HIV should be vaccinated against HBV. Patients coinfected with HIV and HCV should be vaccinated against both HAV and HBV, and should consult a physician on appropriate medical treatments and reduce or abstain from alcohol use because of its effect on the liver.

As treatments for HIV become more effective and HIV-infected persons are able to manage their HIV disease, HCV-related health complications such as liver disease and transplantation will likely become a more critical issue for the coinfected.

## Hepatitis D and E: **Basic Facts**and Prevention

While HDV and HEV are less common in the United States, it is important to be aware of the basic facts and risks for transmission of these two viruses.

### HEPATITIS D (DELTA) VIRUS AND ITS PREVENTION

HDV is a defective virus that requires the helper function of HBV in order to replicate. HDV may either occur as a coinfection (being transmitted at the same time as HBV) or as a super-infection (being transmitted to a person who already has chronic HBV infection). Those with HBV-HDV coinfection may have more severe acute disease and a higher risk of fulminant hepatitis (2%-20%) compared with those infected only with HBV. Chronic HBV infection seems to occur less frequently in persons with HBV-HDV coinfection.

People who have chronic HBV infection who become super-infected with HDV usually develop chronic HDV infection. In long-term studies of chronic HBV carriers who acquire an HDV super-infection, 70%-80% have developed evidence of chronic liver diseases with cirrhosis, compared with 15%-30% of patients with chronic HBV infection alone.

HDV is transmitted in many of the same ways as HBV, although it is less efficiently transmitted sexually and appears rarely to be transmitted from mother to baby. Because HDV requires HBV to replicate, the best way to prevent HDV infection is to prevent HBV, particularly through vaccination. However, there is no product available to prevent HDV super-infection among those who are already chronically infected with HBV; therefore, even those already infected with HBV must continue to receive prevention messages to prevent infection with HDV.

## A Primer for Community Planning Groups

### HEPATITIS E AND ITS PREVENTION

Infection with the hepatitis E virus (HEV) causes symptoms similar to those of the other hepatitis viruses. However, for reasons not well understood, HEV infection has a mortality rate of up to 20% among pregnant women who become infected. HEV is usually transmitted in fairly large outbreaks through water contaminated with fecal matter. It is uncommon in the U.S., most frequently occurring among some travelers newly returned from areas of the world in which HEV is endemic, particularly Mexico, parts of Africa, India, China, and other parts of Central, South and East Asia. The best way to avoid HEV is by drinking only bottled water when visiting affected regions.

# How Can HIV Prevention Community Planning Groups Respond to Viral Hepatitis?

How CPGs choose to address viral hepatitis will likely be as unique as each individual CPG. However, if health departments and their CPGs are interested in incorporating viral hepatitis into the planning process, there are a few steps that they can take to begin:

### **EDUCATION**

CPG members will need to increase their knowledge and awareness of viral hepatitis. Invite persons working in viral hepatitis, such as the state's hepatitis C coordinator, to a CPG meeting to present information on the epidemiology of viral hepatitis in your jurisdiction.

#### **ORGANIZATION**

There will likely be members more interested in viral hepatitis than others on the CPG. These interested members could organize a sub-group of the CPG to specifically examine viral hepatitis and how it relates to HIV prevention and the planning process in your jurisdiction. For example, the California HIV CPG has developed a "Hepatitis C Task Force" which examines HCV in CA, makes recommendations, and then brings those recommendations forward to discuss with the full membership. Organizing a smaller working group within the CPG to address viral hepatitis can be an efficient way to manage the addition of another disease.

#### **ASSESSMENT**

In order for a CPG to understand the prevention programs and resources needed to address viral hepatitis in their jurisdiction, the CPG should conduct a needs assessment and resource inventory of viral hepatitis to determine what resources are available and what is needed.

### A Primer for Community Planning Groups

### **COLLABORATION**

CPGs should work with their partners in immunization, corrections, substance abuse, and STD to comprehensively address viral hepatitis in their jurisdiction. Working collaboratively with these separate public health programs that all have a stake in viral hepatitis will enhance the ability of the CPG to respond to the needs and challenges of viral hepatitis. Additionally, coordination with disparate public health programs will also enhance HIV and STD prevention efforts.

The following profiles of the Rhode Island HIV CPG and the Multnomah County, Oregon HCV CPG illustrate two different approaches that jurisdictions have taken to address viral hepatitis.

### PROFILE OF THE RHODE ISLAND HIV CPG

According to State AIDS Director Paul Loberti, the Rhode Island HIV Community Planning Group (RI CPG) began to address HCV issues as far back as the mid-1990s. Over time, and particularly as the magnitude of the HIVviral hepatitis co-epidemic came into view, the RI CPG became more and more interested in the ways that, by making slight modifications in their HIV prevention planning, they could have a major impact on reducing another viral infection. "The CPG really appreciated that you could 'get two for one' by building HCV into their planning process," said Loberti.

A key factor, he added, has been the CPG's ability to maintain the flexibility needed to add new "hot topics" such as HCV as they emerge. Because the planning process runs according to a fixed yearly plan, it is not always easy to introduce new subjects. But over time, the RI CPG has found ways to fit HCV into discussions where needed, and have increasingly added it directly into their yearly plan. For instance, in the late 90s, the DOH decided in consultation with the CPG to incorporate a phrase into the contracts of all state HIV vendors requiring them to also address HCV and to provide training to these vendors. Next year will be the first time that a yearly plan includes HIV-HCV coinfection as a priority issue and directly addresses prevention concerns.

Another major step occurred when RI's HCV Coordinator, Lorraine Asselin Moynihan, began to serve as a consult-

ant to the CPG. She attends CPG meetings whenever requested, and provides quarterly updates on epidemiology in Rhode Island as well as on larger trends. For instance, at a recent CPG meeting on issues pertaining to men who have sex with men (MSM), she shared articles articulating the vulnerability of MSM to viral hepatitis, particularly hepatitis B. At a CPG session on injection drug users (IDUs), she focused on statistical evidence for the high correlation between unsafe injecting practices and hepatitis C.

In addition to making presentations and taking questions from CPG members, Moynihan also offers individualized attention to the agencies and clients of CPG members. This often takes the form of visits to conduct staff education and updates, but can also involve making referrals for individuals. An overriding theme in her work with the CPG is the need for integration of viral hepatitis services into HIV settings, especially given the high rates of co-infection. However, integration need not be complete. For example, Moynihan is in the process of convening a freestanding advisory group on viral hepatitis, including medical practitioners and patients, who will focus specifically on such issues as extending adequate care to the people living with chronic HBV or HCV who are uninsured or underinsured.

For more information, please contact Lorraine Asselin Moynihan by phone at (401) 222-7544, or email at lorrainem@doh.state.ri.us.

### PROFILE OF MULTNOMAH COUNTY, OREGON: HEPATITIS COMMUNITY PLANNING

One of the first jurisdictions in the nation to implement a formal community planning process for HCV was Multnomah County, Oregon, which has a population of about 640,000 and includes the city of Portland, whose metro area is the state's largest with approximately 1.5 million people. The county has a significant population of heroin users and homeless individuals, and despite active syringe exchange programs, serious concerns about HCV led to the development of a number of grassroots HCV taskforces beginning as early as 1998.

Due in large part to pressure from community activists in the county in 1999, the Multnomah County Department of Health was tasked with constructing a plan and process to address HCV. The current HCV community planning process was the result of both community need and the county's Viral Hepatitis Integration Program, staffed by Coordinator Virginia Schmitz, Social Worker Alison Goldstein, and Health Educator Jessica Guernsey, each of whom has experience in HIV/AIDS.

Because the impetus for HCV community planning in Multnomah County directly from the passionate outcry in the community, the program staff had a great deal of latitude in developing the process. although with no funding specifically dedicated for this purpose. In practice, the HCV community planning model developed in Multnomah County and launched in September 2001 has drawn heavily upon the experience of HIV CPGs, such as through the use of the "nine steps of community planning." An important lesson has been that the group itself has needed to develop its own process, such as the need for more formalized structures. Existing precedents from HIV CPGs could not simply be imported. As a result, the group has taken some time to clarify its role as a planning body. Thus far, it has operated as an autonomous institution, but program staff believe that the logic of integration between HIV, STD, and other infectious diseases may over time lead the group to advocate a

merger with HIV CPGs or the formulation of a "multi-infectious disease" planning body.

As of July 2002, about half of the members are representatives of the County Department of Health, although from a wide range of offices including HIV, STDs, immunization, occupational health, mental health, and communicable disease. About 20% are "consumers," or individuals who are themselves living with HCV. The remainder are composed largely of representatives from other organizations, such as the Oregon state health plan, academic institutions, alcohol and drug treatment, medical, housing, and other social service providers. As with HIV CPGs, a focus is being placed on "parity, inclusion, and representation."

The first several meetings focused largely on issues of building relationships among the group's members, explaining the nature and goal of the planning process, and developing a mission and vision. A more formalized structure was enacted with the creation of four distinct teams, each of which has representation on a separate leadership team. The four teams focus on: Prevention, Education and Outreach; Social Service Coordination; Medical Care and Treatment; and Advocacy. Because a comprehensive resource inventory had already been conducted, the first major undertaking of the planning group has been to draft a county-wide needs assessment, with each team taking the lead on developing the questions for its area of specialization. Two separate surveys are to be conducted, one of providers of physical and mental health and of social services, the other of consumers, including subsets of the general population as well as those already diagnosed with HCV. Upon completion of the needs assessment, a gap analysis is to be conducted and strategies devised for linkages and coordination of care. A larger issue to be tackled is the stigma associated with injecting drug use, which program staff believe may be inhibiting the development of more robust community engagement.

For more information please contact Virginia Schmitz by phone at (503) 988-3030, or by email at Virginia.s.schmitz@co.multnomah.or.us.

### References

- <sup>1</sup> Alter, Miriam J. & Moyer, Linda A. (1998) The Importance of Preventing Hepatitis C Virus Infection Among Injection Drug Users in the United States. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, Vol. 18 (Suppl 1), pp. S6-S10.
- <sup>2</sup> Centers for Disease Control and Prevention (CDC) Recommendations for prevention and control of hepatitis C virus (HCV) infection and HCV-related chronic disease. Morbidity and Mortality Weekly Report 1998; 47 (RR19): 1-39.

www.cdc.gov/mmwr/preview/mmwrhtml/00055154.htm.

- <sup>3</sup> Centers for Disease Control and Prevention (CDC) Frequently asked questions and answers about coinfection with HIV and hepatitis C virus. www.cdc.gov/hiv/pubs/facts/HIVHCV\_Coinfection.htm.
- <sup>4</sup> Goldstein, Susan T.; Alter, Miriam J.; Williams, Ian T., et al. (2002) Incidence and Risk Factors for Acute Hepatitis B in the United States, 1982-1998: Implications for Vaccination Programs. The Journal of Infectious Diseases, Vol. 185, pp. 713-719.

# Appendix A: **Some Evidence from the Public Health Literature**

References for the following cited articles are located in Appendix A, NASTAD's "The HIV-Viral Hepatitis Connection: A Select Annotated Bibliography of the Public Health and Biomedical Literature."

## BOTH VIRAL HEPATITIS AND HIV HAVE A SIGNIFICANT IMPACT ON QUALITY OF LIFE

In an survey, 200 house staff and physicians ranked the impact of HIV and HBV on quality of life (QoL) with a ranking system in which 0=death and 1=good health. The respondents provided scores of 0.833 for asymptomatic HIV and 0.917 for asymptomatic HBV, recognizing that both diseases have an impact on QoL even before the onset of symptoms. Symptomatic HIV was scored at 0.417 and mildly symptomatic HBV at 0.667, indicating significant impairment by both conditions. AIDS (i.e., late stage HIV disease) and severely symptomatic HBV (i.e., cirrhotic complications of liver disease) were provided identical scores of 0.167, indicating a QoL in the lowest quartile. Overall, even HBV with only moderate symptoms was scored lower on the QoL scale than almost all other non-HIV conditions, including moderate stroke, monocular blindness, and severe angina. The authors indicate that their findings should be incorporated into the policymaking process: "Cost-effectiveness studies of HIV interventions should account for the effect of the intervention on both mortality and morbidity, particularly when the morbidity of the condition is severe (p. 83)." (Owens, Cardinalli, and Nease 1997)

Even asymptomatic liver disease can lead to significant psychological distress. In a study of 80 subjects with minimal hepatitis or cirrhosis, 64 had minimal or no physical symptoms yet 50% reported distress, which was severe for 15%. Mental health diagnoses were possible among 45% of the asymptomatic individuals. These findings

were attributed to concern about the disease and/or to possible subtle changes in central nervous system functioning. (Davis et al., 1998).

## THERE ARE SERIOUS INTERACTIONS BETWEEN TREATMENTS FOR HIV AND VIRAL HEPATITIS

Both HIV and HBV can be treated with the antiviral medication lamivudine. One study revealed that 18 months of therapy led to loss of HBV antigens, a durable result. (Dienstag, 1999). Recombinant interferon alpha therapy has also been reported to be effective, particularly with active chronic HCV patients who are HIV-positive and also on zidovudine and who have CD4+ cell counts below 200 (Del Pozo et al., 1998).

In a case study of a patient co-infected with HIV and HBV, Joseph, Chandramani, and Cox (2000) reported that the patient died after treatment with HAART. "Even though the cause for his deterioration is unclear, it is possible that the liver damage could have been more severe than initially thought, subsequently aggravated by drug therapy. This case illustrates the need to exercise caution when co-infected patients are considered for treatment, especially those with mildly de-compensated cirrhosis and the need to include liver histology in the evaluation process."

## HIV AND VIRAL HEPATITIS AFFECT MANY OF THE SAME GROUPS

A study of French intravenous drug users not reporting infection HIV or HCV reported numerous overlapping risk behaviors which could lead to HIV and HCV sero-conversion, including lending and borrowing of drug paraphernalia, inconsistent use of condoms, having multiple partners and/or engaging in prostitution, and not using clean needles. Associated behaviors and characteristics included alcohol abuse, homelessness, low educational level, and cocaine use. (Vidal-Trecan et al., 1998)

A study of socioeconomic status (SES) among sex workers in Brazil (Lurie et al., 1997) found a strong correlation between SES and disease acquisition. Those with higher as opposed to lower SES had lower rates of HIV (4% vs. 17%), syphilis (24% vs. 66%), and HBV (26% vs. 52%).

HCV can also be transmitted perinatally; 13 of 403 children born to women who were HCV-positive but HIV-negative became infected with HCV. (Resti et al., 1998) HIV-positive women are even more likely to transmit HCV perinatally (Berger, 1998).

An American Medical Association policy statement on "Health Care Needs of Gay Men and Lesbians in the United States" states that "all forms of hepatitis can occur in gay male patients. Because of the risk for hepatitis B infection, sexually active gay and bisexual men should receive the hepatitis B vaccine. In general, gay men are at greater risk for contracting hepatitis B than hepatitis C virus infection, which is frequently transmitted by injecting drugs." (JAMA 1996).

Health care workers are also at risk from both HIV and HCV. For instance, policy guidelines established by the American Association of Colleges of Nursing (1997) recognize the dangers of both viruses. Noting that HBV kills 200 health care workers annually, the policy calls for mandatory HBV vaccination.

## THERE MAY BE AN IMPACT ON DISEASE PROGRESSION OF COINFECTION WITH HIV AND VIRAL HEPATITIS

A natural history study by Gilson et al. (1997) indicates that HIV infection is associated with higher HBV DNA polymerase activity in HBV carriers. HIV infection increases HBV replication, leading to increased and prolonged HBV infectivity. However, it also suggests that HIV-related immunosuppression gives rise to less active liver disease. (There was no evidence of an important effect of HBV carriage on HIV disease progression.) However, this finding was challenged in a letter to the editor by Bonacini (1997) citing evidence "against the theory that HIV leads to 'intrahepatic' immunosuppression (p. 1790)."

Another case study indicated that simultaneous occupational infection with HIV and HCV led to rapid hepatic failure and death. The authors speculate that acute co-infection could "interfere with initial immune response to HIV and higher HIV burden and more rapid HIV progression (p. 28)." (Ippolito et al. 1998)

### VIRAL HEPATITIS PREVENTION IS A MAJOR CHALLENGE

A cohort of drug users undergoing methadone maintenance therapy (MMT) in Geneva, Switzerland were tested over time for HIV, HBV, and HCV infection. The prevalence of all three viruses at entry to the program declined markedly over time. When comparing those who entered MMT before 1988 versus those who entered after 1993 by which time extensive prevention outreach had been undertaken, HIV seroprevalence rates dropped from 38.2% to 4.5%, HBV rates from 80.5% to 20.1%, and HCV rates from 91.6% to 29.8%. "The data suggest that [drug users] have changed HIV risk-taking behavior in response to HIV prevention campaigns (p. 2059)." (Broers et al., 1998)

Van Beek et al. (1998) conducted a retrospective cohort study of injecting drug users in a primary healthcare facility in

## Needle exchange programs are clearly inadequate as a comprehensive HIV/HCV reduction program.

Australia that revealed that HIV seroincidence was 0.17 per 100 person years but that HCV seroincidence

was more than 100 times greater at 20.9 per 100 person years – and 75.6 per 100 person years among those aged less than 20 years. In an editorial commentary on the study, Coutinho (1998) noted that "success in preventing HIV has not been mirrored for hepatitis C." Noting the greater efficiency of blood borne transmission of HCV than HIV and higher population seroprevalence rates of HCV than HIV, he notes that prevention messages crafted for HIV are insufficient for HCV among injecting drug users and that prevention messages should be expanded to include "indirect" sharing of cotton, water, and other equipment. This is the case even in Australia, which has had expansive harm reduction policies in place.

Needle exchange programs are clearly inadequate as a comprehensive HIV/HCV reduction program. Strathdee et al. (1997) conducted a study with a prospective cohort of injecting drug users in Vancouver, Canada, which has had a needle exchange program (NEP) since 1988 and distributes 2 million needles annually. Although 93% had attended the NEP, HIV seroprevalence was 23% and HCV seropreva-

lence was 88%. "Whereas NEPs are crucial for sterile syringe provision, they should be considered one component of a comprehensive program including counseling, support, and education."

The value of methadone maintenance therapy for HCV prevention is also unclear, given that although such programs do decrease injection episodes even a single relapse into injecting behavior can lead to transmission due to the high efficiency of HCV transmission (Crofts et al., 1997). "Patients who are seropositive for HCV need counseling about all aspects of their infection, including methods to minimize the risk of further transmission. This counseling must emphasize not sharing any injecting equipment or allowing any blood contamination of objects or surfaces which can carry the virus to others (p. 1004)." This advice is relevant for both HCV-positive and HCV-negative patients due to the risk of re-infection with other subtypes of HCV.

A British cohort of injectors of anabolic steroids had dramatically lower levels of HIV and HBV than cohorts of heroin or amphetamine injectors, and also rarely shared needles suggesting the need to treat steroid injectors differently than other IDUs (Crampin 1998).

A survey of British health care providers revealed that those who believed they could identify patients at high risk for HIV or viral hepatitis were less likely to practice universal precautions. The article argues that effective implementation of universal precautions requires addressing underlying beliefs among health care workers (Cockcroft 1994).

#### A Plus: The Role of Vaccination

Although vaccines have successfully been developed for HAV and HBV, they will be harder to develop for HCV since the virus mutates more rapidly. In addition, the same individual can be infected with multiple subtypes of HCV (Berger, 1998).

Among adolescents, parental involvement can be important. Moore-Caldwell et al. (1997) determined that the more informed parents are about HBV, the lower the reported level of risk-taking behaviors among adolescents.

### A Primer for Community Planning Groups

Despite complications, it is possible to achieve compliance with the three-shot course of hepatitis B vaccination. Among a cohort of HIV-positive former heroin addicts in methadone maintenance, 86% completed the six-month vaccination series (Borg et al., 1999). After an educational campaign and a program of in-school vaccinations, two-thirds of a middle school population received the full three doses of the hepatitis B vaccine. Of those without pre-existing immunity to HBV, 96% developed protective levels of antibodies to HBV (Cassidy 1995).

Mass hepatitis A vaccination is not seen to be cost-effective, but could be for particular areas or populations (O'Connor, Imperiale, and Singer, 1999).

## Appendix B: Glossary

**Acute infection** Newly acquired infection.

Asymptomatic An absence of symptoms of dis-

ease.

**Chronic infection** Long-lasting infection, usually

defined as lasting more than six

months.

**Cirrhosis** Scarring of the liver; can be

caused by chronic HBV and

HCV infection.

**Defective Virus** A virus that needs the presence

of another virus to cause infection; a defective virus cannot by itself cause infection. Hepatitis D virus (HDV) can only cause infection if it is transmitted at the same time as HBV, or if it is transmitted to someone already

infected with HBV.

**Endemic** A condition that is occurring in a

population at all times.

Fulminant hepatitis Massive death of liver tissue

resulting in liver failure.

**Genotype** A subtype of a virus which can

be identified by examining the genetic material of the virus.

**Hepatic Failure** 

When the liver does not perform

its functions.

**Hepatitis** 

Inflammation of the liver.

**HIV/HCV** Coinfection

Infection with both the human immunodeficiency virus (HIV) and the hepatitis C virus (HCV).

**Immune Globulin** 

A preparation of antibodies available for short-term protection against HAV and for persons who have already been exposed to HAV. Immune globulin must be given within two weeks of exposure to HAV for maximum

protection.

Intrahepatic

Within the liver.

**Liver Cancer** 

A type of cancer caused by cancerous cell growth in the liver.
Chronic infection with HBV or
HCV can lead to liver cancer.

Mucosal

A membrane rich in mucous glands. Mucous membranes line body passages and cavities that connect directly or indirectly with the exterior.

Opportunistic Infections

In the context of HIV/AIDS, these are infections that people with HIV/AIDS are more susceptible to because of their weakened immune system. In a true sense HCV does not fit the definition of an opportunistic infection (OI), however, it is classified as an OI because of the probable complications caused by infection with these two viruses.

**Socioeconomic status** A term used to refer to the (SES) amount of income of an individ-

ual or family.

**Standard Precautions** 

Precautions used in health care settings to protect against the transmission of blood borne infections, e.g. wash hands frequently with soap and water; immediately discard needles and sharps into protective containers.

**Super-Infection** 

Infection with more than one

type of viral hepatitis.

**Viral Hepatitis** 

Inflammation of the liver caused by a viral infection. HAV, HBV, HCV, HDV, and HEV are five major types of viruses that cause

viral hepatitis.

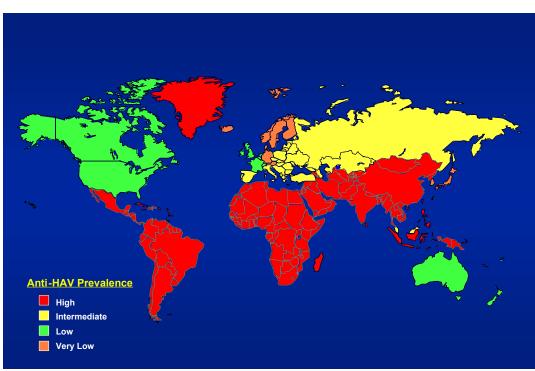
Viral Henatitis Infection with more than one **Re-infection** subtype of viral hepatitis.

**Viral Replication** 

The process by which a virus takes over living cells and uses them to produce new particles.

### Appendix C:

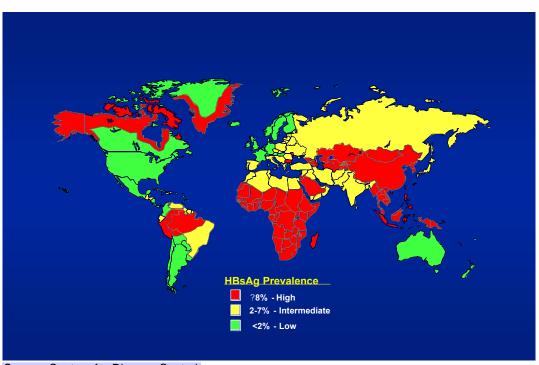
## Geographic Distribution of HAV Infection



Source: Centers for Disease Control and Prevention. Available on the world wide web at: www.cdc.gov/ncidod/diseases/hepatitis/slideset/index.htm

### Appendix D:

## Geographic Distribution of HBV Infection



Source: Centers for Disease Control and Prevention. Available on the world wide web at: www.cdc.gov/nci-dod/diseases/hepatitis/slideset/index .htm

4

**Integrating Viral Hepatitis Services into Existing** 

## HIV and STD Clinics

# Integrating Viral Hepatitis Services into Existing HIV and STD Clinics

s increased awareness about viral hepatitis grows, HIV/AIDS/STD programs across the country are striving to meet the needs of their clients at risk for or infected with one or more of the types of viral hepatitis. Many of the clients seeking services at HIV/STD clinics would benefit from viral hepatitis prevention services (e.g. hepatitis A and B vaccine and hepatitis C counseling and testing). HIV/STD clinics are responding to this need by integrating viral hepatitis services in their existing programs and clinics. Providing integrated services emphasizes the importance of recognizing clients from a holistic perspective, as persons presenting with multiple needs and multiple risks. The focus of service delivery is altered to more broadly address all the risks that accompany certain behaviors.

While integrating services is sound and efficient public health practice, the challenges to integration often present formidable barriers to program implementation. Financing the additional services is a substantial concern for HIV/AIDS/STD programs. Clinics often piece together funds from numerous sources in order to pay for expensive hepatitis C tests and vaccine for hepatitis A and B, and programs often face uncertainty about their ability to sustain funding. And while many HIV/STD programs are eager to add hepatitis services, it is not uncommon for clinic staff to feel hesitant about the addition of new services. Adding new services requires increasing staff capacity to deliver the services, necessitating intensive training to develop staff competence. The impact of additional services on clinic flow and client waiting time is also a frequently cited concern by clinic staff.

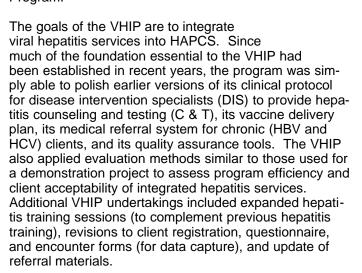
Integrating Viral Hepatitis Services into Existing HIV and STD Clinics

Perhaps most significantly, HIV/STD clinic staff are rightfully concerned about counseling and testing clients for hepatitis C when there is still very little treatment and referral infrastructure available. This concern resonates strongly with those who worked in HIV and remember that before the advent of highly effective antiretroviral drugs, the AIDS Drug Assistance Programs (ADAP) and the network of care providers, there was little to offer persons infected with HIV. Ultimately, these are concerns that must be addressed individually by programs, involving all key stakeholders involved in integration.

Despite these challenges, HIV and STD clinics are successfully implementing viral hepatitis services into their existing clinic services. The six state and county health departments profiled in this report reflect the diversity of the programs, emphasizing that there is no "right" way to integrate services. Seattle-King County, Washington; Texas; Montana; Virginia; San Diego County, California; and Illinois have all integrated viral hepatitis services into their existing HIV/STD clinics. The scope of the projects and services provided vary, but all do share some key characteristics. All agree that working collaboratively with all parties involved in making the integration work has been instrumental to their success.

In 1991, HIV/AIDS Program Clinical Services (HAPCS) staff, Public Health -- Seattle & King County (S/KC), began to receive training to expand services to include risk screening, serologic testing, and vaccination for hepatitis A (HAV) and hepatitis B (HBV) viruses. In 1998, HAPCS services were extended further to include hepatitis C virus (HCV) EIA testing.

In early 2000, the S/KC HIV/AIDS Program formally implemented a Viral Hepatitis Integration Project (VHIP), with funding from the Centers for Disease Control and Prevention (CDC). Data collection began in May of 2000. The program is led by principal investigator, Bob Wood, M.D. and epidemiologist, Linda Shih, both of the HIV/AIDS Program.



HAPCS services are provided to a client population that is primarily comprised of men who have sex with men (MSM) and injection drug users (IDU). Clients are eligible for the VHIP if they are seeking testing for HIV or if "HIV testing" is cited as "reason for visit" on the encounter form. The number of eligible clients who actually receive hepatitis C/T is determined by the following criteria: if a) "hepatitis testing" is also recorded as "reason for visit" on encounter form; or if b) "vaccine recommended" (or "declined") is noted on encounter form; or if c) "hepatitis A/B/C testing done" is noted on encounter form. Hepatitis risk is assessed via the Hepatitis A, B, and C Risk Factor Screening, Serologic Testing, and Counseling Protocol (used by DIS) and/or the HIV/AIDS Hotline which is run

by HIV/AIDS Program.

SEATTLE-KING

COUNTY

Since 1986, the HIV/AIDS Program has provided both anonymous and confidential services including HIV C & T, and more recently, services for STD and the viral hepatitides. Clients who register confidentially have records that are only

identifiable by code (which is stored on a computer drive, regularly removed, and

stored under separate lock and key). Clients who register anonymously are instructed on how to create a standard anonymous code, which is generally reproducible at subsequent visits to public health clinics. These codes enable records to be linked without revealing the client's actual identity. All paper records are housed in a locked

room, accessible only to clinical staff with need for access. Clinical staff signs a yearly oath to maintain client data confidentiality.

The HIV/AIDS Program requires that clients read and sign a consent form prior to HIV testing; the form also includes general consent to treat and covers some hepatitis services. Consent for immunization is obtained on a separate form. Test results are provided either in-person, at a follow-up visit about one week later, or by phone. Clients who opt for phone results must recreate their confidential or anonymous chart identifier, as well as provide a key word, before they can obtain their test results.

Amendments to guidelines and protocols for clinical services are discussed between key VHIP staff and clinical staff, when related issues arise; modifications are incorporated into clinical staff training sessions.

The medical referral system is directed at clients who test positive for acute or chronic hepatitis B infection, and/or hepatitis C infection; these persons are referred for treatment with their personal health care provider, or at the Hepatitis & Liver, or Infectious Disease Clinics. Both clinics are located at Harborview Medical Center, the primary hospital in the region.

All interested clients may not be readily immunized because there are 14 sites in greater Seattle involved with VHIP, and just one immunization nurse. Thus, interested clients who are seen by disease intervention specialists (who cannot administer vaccines in Washington State) at other sites are referred for vaccine to the immunization nurse (by appointment) or the STD Public Health Clinic.

For more information please contact Linda Shih at 206-205-6120 or Linda.shih @metrokc.gov

#### Integrating Viral Hepatitis Services into Existing HIV and STD Clinics

Integration of viral hepatitis into HIV C&T was first discussed in 1998 in a working group specially convened by the Texas Department of Health (TDH), according to Texas AIDS Director Casey Blass. At that time, it was decided to discuss integration in the white paper on hepatitis C produced by the TDH, "Hepatitis C: An Emerging Health Concern For Texans," as well as in the draft legislation that was to be introduced to the Texas legislature. The rationale was simple: avoiding the duplication of services by building on existing infrastructure. "Buy-in" for the idea of integration also came from local health departments that were part of the working group.

The basic concepts on how integration would be implemented were also generated by the group, based in part on some pilot work done by the Austin-Travis County Health Department with funds provided by CDC. The TDH then spent a year preparing the trainings and developing the guidelines that would be needed to carry out integration; clinic protocols were also developed through the same process. It was deliberately decided to keep the working group small in order to be able to continue to work on a consensus basis, and also due to early limitations of funding.

Counseling for both hepatitis B and C was integrated into the HIV C&T training, with all HIV counselors trained on viral hepatitis issues. Optional continuing medical education is being offered in the state for nurses, drug counselors, and others who need additional hours of training.

The counseling applies a client-centered model with two areas of emphasis. The first is building the client's knowledge base both about the types of viral hepatitis and about how the viruses can be transmitted. The second part emphasizes skills building within the tradition of HIV prevention counseling,

focusing on such areas as condom use and safer injection practices. The counseling sessions are based on "starting where the client is and then filling in gaps." Thus, for instance, if a

client has a history of injection drug use, the counselor will ascertain existing knowledge and skill sets, and then provide additional information as needed.

According to Blass, the availability of viral hepatitis counseling and testing is proving to be "an additional hook" helping to bring at-risk individuals into HIV C&T sites.

All clients attending HIV C&T sites not only receive viral hepatitis counseling but are potentially eligible for testing as well,

depending upon where the client's

risk factors place him or her on the CDC viral hepatitis risk hierarchy. The "cut-off" point of risk that triggers a test is determined by each site, ultimately exercising their judgment in light of budget limitations. HIV and viral hepatitis testing is generally done together, but if they prefer clients can have either test individually; if requested, the sites will also provide an anonymous HIV test separately from the confidential viral hepatitis test.

All those who test positive for HCV are eligible for HAV and HBV vaccination. Data is collected for each client using a modified version of the CDC scantron, with an addendum for the collection of additional risk information. Quality assurance is built into contract performance. In addition, data provided back to the Texas Health Department is analyzed to cross reference viral hepatitis positivity rates by risk groups, to be sure that counseling and testing are reaching those at highest risk.

For more information, please contact Casey Blass at 512-490-2515 or casey.blass@tdh.state.tx.us

In the state of Montana, 15 HIV/STD counseling and testing sites have been contacted regarding the protocol for screening for hepatitis C. In the absence of new funding, Montana has been able to promote the integration of HCV screening into existing clinic protocol by raising the MONTAN awareness of the clinics regarding the urgent need for such a service. Statewide trainings have been provided to health care personnel. A media campaign including TV and radio public service announcements was developed indicating the risk factors for viral hepatitis and encouraging those at risk to seek screening. The early steps of the initiative, as well as funding for HCV tests and state HCV hotline, were supported by an unrestricted educational grant from Schering-Plough and a CDC

Montana faces the difficulty of being a geographically huge state with only 900,000 widely dispersed people, many of whom may be hours away from C&T sites and potentially hard to reach. However, the program has grown dramatically since its humble beginnings in 1997 as a registry of acute and chronic HCV cases, now having identified over 4100 people with HCV in the state.

Enhanced Laboratory Capacity grant.

The key to achievement of "buy-in" from clinics was an emphasis on the great deal of overlap between HIV and viral hepatitis prevention, underscoring that adding viral hepatitis need not involve creating new programs or infrastruc-

ture but simply extending current protocol. The state developed an HCV screening and counseling checklist, which has been widely adopted by local clinics. In 1999 there was an increase in

requests for screening made directly to clinics by clients following an outbreak of hepatitis B in the state, which resulted in ten deaths among individuals coinfected with hepatitis C. This helped to persuade clinic staff of the importance to provide hepatitis C services. And while state officials did not mandate

that all HIV C&T sites provide HCV screening, they did "strongly recommend" it. Inclusion of HCV is also now recommended as standard of performance for contractors, and coordination has been undertaken with CBOs as well as some grassroots advocacy groups for ex-convicts and injection drug users.

A successful joint conference on HIV/HCV/STD was held in June of 2002. Several challenges remain, including tracking and follow-up with those who test positive for HCV, cultivating interaction with the public health establishment in a population that prizes its privacy, and securing additional funds for clinic-based services.

For further information, contact Marci Eckerson at 406-444-1805 or Joyce Burgett at 406-444-5580.

The Virginia Department of Health (VDH), Division of HIV/STD has a history of providing integrated services: in 1986 VDH successfully integrated HIV services into its STD clinics. In 2000 discussions began around integrating viral hepatitis services into the existing VIRGINIA HIV/STD clinics. VDH estimates that approximately 97,000 persons in the state are infected with hepatitis C virus (HCV), and of those, only about one-third know their status. Integrating services into settings that reach persons at high risk for HCV was a logical step towards identifying those who are HCVinfected and unaware of their status. There was a strong sense among persons involved that adding viral hepatitis services to existing clinics would have minimal impact on the services already offered. The Division of HIV/STD felt that because of shared risks. STD and HIV messages provided a good lead-in for viral hepatitis prevention messages.

VDH focused its integration efforts on six local STD clinics, in the following Virginia cities: Norfolk, Chesapeake, Winchester, Alexandria, Petersburg and Richmond. These six sites capture the diversity of the state of Virginia and allow for a broad reach of services. HCV counseling and testing and hepatitis A and B vaccine are offered to clients at increased risk of infection. CDC hepatitis screening criteria (e.g. ever received a transfusion, ever used a needle to inject drugs), is followed at one of the six sites that receives funding through CDC's viral hepatitis integration project. The five other sites follow an "enhanced" screening criteria, using standard CDC criteria and also screening clients who report male sex with men (MSM) as a risk factor and/or multiple sex partners

(MSPs), defined as sex with 5 or more partners in a year/ 20 or more partners in a lifetime.

The rationale for using and enhanced screening criteria is that VDH is able to assess the cost-effectiveness and benefits of including these additional risk factors.

The goal of this integration project is to assess which at-risk clients should be targeted for services within the STD clinic setting and to provide a model for expansion across the state.

This project will also help determine the effectiveness of integrating hepatitis services into an existing STD/HIV clinic.

One of the challenges of integrating for the Division of HIV/STD was learning about immunization. The Division of Immunization within VDH provided hepatitis A and B vaccine and logistical training on administration of vaccine. Unique computer codes were assigned to the vaccine provided in order to track initiation and completion rates. The HIV/STD clinics provide the first dose of vaccine to interested clients onsite, eliminating the potential barrier of referring clients to the immunization clinic. After the first dose, however, clients are instructed to receive the remaining doses at the immunization clinic. The reminder system, which involves providing the patient with an appointment card with a schedule for the second and third doses of vaccine that the immunization clinic has used historically, is also followed for HIV/STD clinic clients. The traditional protocol is followed in order to accurately compare whether the clients who attend the HIV/STD clinic not seeking hepatitis services will have similar or different rates of completion than persons attending the immunization clinic specifically for hepatitis services.

The biggest challenge that the Division of HIV/STD found in integrating hepatitis services into HIV/STD clinics included providing sufficient education and training to HIV/STD staff in order for them to feel comfortable educating and providing services to clients. Traditionally, acute hepatitis was located in the Division of Surveillance and Investigation and perinatal hepatitis B was located in the Division of Immunization. The addition of a "new" disease required in-depth training on the basics of viral hepatitis; training for STD nurses on how to administer and document vaccine usage; counselor training on viral hepatitis prevention messages and how to elicit hepatitis risk information; and the revision of lab slips and paperwork to include viral hepatitis. clients who are the The six local health depart-"average" clinic clients, ments determined individually how to integrate hepatitis services into the flow of their clinics. specifically seeking

viral hepatitis An additional challenge of integrating viral hepatitis services services. was ensuring fidelity to protocol. It is important for the HIV/STD clinics to capture HIV/STD clients who are the "average" clinic clients, and not persons specifically seeking viral hepatitis services. The staff was concerned that individuals not at risk for hepatitis may hear that the clinics are offering viral hepatitis services and seek vaccination and testing, and clinic staff would have to deny servies. In response to these concerns, the Division of HIV/STD hepatitis program carefully targeted their radio ad campaign and advertising services to persons who had ever received transfusions or used a needle to inject drugs. Specifically tailoring this message helped reduce the number of "worried well" coming into the clinic for hepatitis screening and other services.

Overall, clinic staff report that integration has gone smoothly. Staff report feeling confident in their ability to educate clients and do not feel that the additional service adds significant time to client stay at the clinic, or has a negative impact on other services provided by the clinic.

Preliminary analysis of the data have found that 59% of persons testing positive for hepatitis C report IDU risk factor, 17% report a history of STD or current infection and 16% report multiple sex partners as the risk factor. Further analyses will determine the cost ver-It sus benefit of using the standard is important

for the HIV/STD

clinics to capture

and not persons

CDC screening criteria compared to the enhanced screening criteria.

> For further information, contact Theresa Henry at 804-786-6267.

#### Integrating Viral Hepatitis Services into Existing HIV and STD Clinics

In accordance with the CDC's recommendation to vaccinate STD/HIV clinic clients against hepatitis B, the Illinois Department of Public Health (IDPH) established two comprehensive hepatitis B pilot prevention programs in existing STD clinics settings in 1999. The two STD clinics incorporated hepatitis B education, counseling, seroprevalance and vaccination services into existing STD/HIV services. Data collected in 1999 from risk assessment survevs completed by clients attending IIINOIS the two hepatitis B prevention pilot sites indicated that 6 percent (67/1,122) of male clinic clients reported sexual activity with males (MSMs). Of these 67 clients, 35 (52 percent) were vaccinated for hepatitis B. Almost 3 percent (51/1,973) of the clients reported injection drug use (IDU) as a risk factor, with 29 (57 percent) accepting hepatitis B vaccine. Overall, 47 percent of clients (926/1973) were vaccinated against hepatitis B.

The success of the pilot programs led the IDPH to offer the hepatitis B vaccination initiative to all STD clinics in Illinois (excluding Chicago, which receives separate federal funding for STD and immunization initiatives). Following a series of training workshops in February 2000, 27 additional STD clinics revised their operating protocols; signed a memorandum of understanding; expanded clinic services to include hepatitis B prevention counseling, education and vaccination services; and agreed to utilize a standardized risk assessment survey to capture client risk behaviors for STD/HIV/hepatitis. These clinics provide services to individuals at risk for a variety of diseases, including HIV, hepatitis, syphilis, gonorrhea, chlamydia and other STDs. Staff have been trained to give individualized counseling to clients to assist them in developing strategies to reduce the risk of acquiring these diseases.

In the fall of 2000, IDPH was able to expand hepatitis prevention activities within STD clinics with funding from a CDC Viral Hepatitis Integration Project (VHIP) grant. IDPH staff established six pilot health department sites to provide targeted hepatitis A and B vaccine to MSMs and IDUs and hepatitis C testing to IDUs. Local health departments (LHDs) were selected based on population risk data, high STD morbidity and the ability to integrate comprehensive prevention services for hepatitis A, B and C into existing HIV and STD prevention services. The VHIP grant enabled IDPH:

- To assist the six local health departments in integrating hepatitis A, B and C prevention efforts into existing services for at-risk clients being served in their STD clinics;
  - To explore the feasibility of expanding hepatitis prevention services into other settings that reach clients at increased risk of acquiring hepatitis;
    - To support the costs of administering hepatitis A and B vaccines;
    - To provide serological screening of IDUs for hepatitis C;
    - To collect, tabulate and analyze data; and
  - To provide feedback to local health departments on progress toward meeting viral hepatitis prevention objectives.

Staff from IDPH's STD and Immunization sections provided initial training and ongoing technical assistance to the six pilot sites to help them prepare for and maintain integration of the additional services. The training focused on identifying and counseling at-risk persons with effective messages to prevent hepatitis and its transmission; provided an overview of the epidemiology of hepatitis A, B and C, interpretation of serologic test results and prevention of progressive disease; addressed specific IDU-related issues, including information on common terms used by injectors and reasons why certain paraphernalia carry risks for acquiring hepatitis: provided specifics on integrating hepatitis prevention messages into existing client-centered counseling; and addressed data collection and hepatitis reporting procedures. Staff from pilot sites are updated regularly through one-hour phone meetings every other month, which allow site staff ample time for questions and discussion on progress in meeting stated objectives. To meet the demand for vaccine for this integration initiative, IDPH targeted more than \$650,000 in federal and general revenue funds to purchase hepatitis A and B vaccine for these at-risk populations.

In the six pilot sites, every VHIP client completes a behavioral risk assessment survey. The risk assessment surveys are submitted to IDPH weekly for data entry and analysis. One of the most significant accomplishments of the existing hepatitis integration initiatives undertaken by IDPH was the development and maintenance of a Microsoft® Access database infrastructure that links data from client-completed risk assessment surveys with data from laboratory results and vaccina-

tion records. The existing infrastructure at each site allows project staff to target MSM and IDU populations through various HIV outreach projects at county juvenile detention centers, county jails, local drug treatment centers, needle exchange programs and various agencies that serve MSM populations.

This data infrastructure allows the continual monitoring of disease and service trends and allows staff to make informed decisions regarding program service delivery. Based on risk assessment surveys submitted by the VHIP pilots from January 1 - December 31, 2001, a total of 11,363 clients were provided viral hepatitis prevention messages. Within the two risk-related populations, 351 clients indicated IDU and 394 indicated MSM as a risk factor. A total of 144 of the eligible 262 (55 percent) IDU clients began hepatitis B vaccination. A total of 127 of the 290 (44 percent) IDUs eligible for hepatitis A vaccine began the series. A total of 151 of the 278 (54 percent) eligible MSM clients began hepatitis B vaccination. Of the 394 MSM clients, 328 were eligible to receive hepatitis A vaccine; 134 (41percent) received the vaccine.

Of the 1,113 specimens collected from clients in the 2001 VHIP projects, 116 (10.4 percent) were confirmed to be RIBA positive for hepatitis C and four (0.4 percent) specimens tested positive for hepatitis B surface antigen. Serologic screening for hepatitis B was eliminated due to the low number of clients identified with chronic hepatitis B infection. The cessation of hepatitis B screening also generated enough cost savings to continue providing hepatitis C screening services for IDUs for the remainder of year two of the project period.

Pilot project staff continue to work with the communicable diseases staff in the local health department to ensure that all hepatitis C-positive persons are provided information about their sero-status and that appropriate care and necessary referrals are provided to these individuals. The need to provide vaccination services to sex and needlesharing contacts of hepatitis C carriers is routinely stressed and assistance in notifying contacts is offered.

VHIP pilot sites participated in collecting data on the amount of time spent with clients during their visits to the STD clinics. The goal of the time study was to examine the length of each client's visit (including waiting time and time in which he/she had the opportunity to interact with clinic staff) and to identify what impact, if any, the implementation of expanded hepatitis prevention services had

on these waiting and interaction time periods. All sites identified a week when staffing patterns were expected to be "normal" during late January, which served as the "control" or "pre-test" period for collecting data for this time study. The data collection process was repeated in mid-April or May, given "normal" staffing patterns and the consideration that expanded hepatitis prevention services were fully integrated. This final data collection process was considered the "case" or "posttest" portion of the time study.

All key staff were aware that IDPH was requesting the time study to determine what impact the integration of comprehensive viral hepatitis prevention services had on STD/HIV clinic flow and services. Results of this limited time study indicate that the pilot clinics were able to integrate comprehensive hepatitis prevention services into STD/HIV clinic services without increasing the client's clinic visit time for several reasons:

• Pilot staff used the time study to review redundant and time wasting episodes and practices after the pre-test assessment phase and to work with staff to optimize interaction periods with the client to ensure improved services and clinic visits.

hepatitis

services can be

successfully

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clinics, but doing so

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monitoring and

- Pilot staff embraced the opportunity to offer hepatitis prevention services and encouraged all clinic staff to promote and integrate hepatitis prevention into other STD/HIV services.
  - Some pilots acquired additional clinic staff to provide integrated services.
- Clinics routinely used written materials (pamphlets, posters, informational flyers) and videotapes to prompt clients to become engaged in hepatitis prevention initiatives.

The Viral Hepatitis Integration Project has demonstrated that comprehensive viral hepatitis services can be successfully integrated into STD clinics, but doing so requires continuous monitoring and follow-up with key staff. Additional hepatitis prevention dollars are necessary to expand services to all Illinois STD clinics and to other venues providing services to MSMs and IDUs and to ensure medical management resources are available for clients who test positive for hepatitis C.

For further information, please contact Richard Zimmerman at 217-782-2747 or rzimmerman@idph.state.il.us.

The San Diego County Sexually Transmitted Disease Program, under the leadership of Robert A. Gunn, MD, MPH, began receiving program support from CDC in 1997 to implement a hepatitis B vaccination Demonstration Project designed to reach high-risk adults and adolescents. While many community sites were enrolled in the Demonstration Project1, the first clinical sites targeted for integration of HBV immunization were the Public Health STD clinics. Within a few years, the program was expanded to include hepatitis B and C screening in the STD clinic and other settings including the HIV Counseling and Testing Program sites. Terry Cunningham, Chief of the Office of AIDS Coordination in San Diego County, was committed to bringing much requested STD and hepatitis services to the HIV Counseling and Testing Program and supported integrated services. By October 2000, universal hepatitis B and C testing was piloted at San Diego County's primary HIV counseling and testing site, and currently several HIV county sites offer hepatitis B and C testing based on the individuals risk profile. The county health department's primary STD clinics offer universal hepatitis B vaccination, selective riskbased vaccination for hepatitis A, selective HCV and HBV screening, and HIV counseling and testing. Services are also offered at several community programs that see a high number of injection drug users (IDUs) and men who have sex with men (MSM).

On an annual basis, the San Diego program provides hepatitis B vaccination to greater than 7,000 high-risk persons; hepatitis A vaccination to greater than 1,700; and HBV and HCV screening to greater than 3,500 persons

accessing STD clinics, community sites, and HIV alternative counseling and testing sites (ATS). Additionally, outreach and education efforts reach more than 20,000 persons annually. Persons who are identified with HCV infection via testing at the STD SAN DIEGO COUNTY or ATS clinic are provided with counseling, education, and referrals. For a period of two years, those who agreed to participate were interviewed at 1, 3, 6, and 12 month intervals to assess follow-up care and to document behavior change. These follow-up interviews will conclude in the next 6 months and the data will be analyzed for reporting and publication.

> Due to considerable experience in integrating hepatitis services, San Diego has worked through many of the challenges that come with adding new services into a busy clinic setting. For example, in the HIV testing sites, clinics have learned to effectively manage providing both anonymous HIV testing and confidential hepatitis B and C and STD testing. In order to address the complication of a client wishing to anonymously test for HIV and confidentially test for hepatitis, two tubes of blood are the drawn from the client, and two different sets of numbers, which are not linked, are placed on the tubes of blood. The client is then given a self-completed "registration form", which collects their name and basic demographic data. to complete. The registration form and the lab slip, which also indicates risk information, are both affixed with a sticker containing the same number as affixed on the tube of blood, linking the three together. Clients are then instructed to place their completed registration form in a lock box. They are then given an information sheet that provides the phone number and

hours available to call and receive test results. The hepatitis specimen tube and the client completed "registration" form are matched via the number by the Public Health Laboratory staff. "This process has provided clients seeking anonymous HIV testing with the security that their STD registration information is not part of their anonymous HIV testing information," states Denise Borntrager, Clinic Services Coordinator of the HIV Counseling and Testing Program.

San Diego soon learned that clinic clients found calling a number to receive their hepatitis test results over the phone to be inconvenient; clients would return to the clinic to receive their anonymous HIV test result and were frustrated that they could not get their hepatitis result in the same visit. In response, the clinic adjusted protocol to allow for the provision of hepatitis results at the clinic if the client is interested. Now, when a client returns to Many the clinic for results, counselors such clients probe as to whether there were any other tests taken that have no or limited they would like to get results for. If a client indiaccess to services, no cates that he or she would like to get their hepatitis test results, the counselor not qualify for any explains that the client's government name is needed in order to retrieve the results. If the assistance client is comfortable with this the counselor provides the programs. client with results on site. San Diego has learned that most clients have no reservations with sharing their name. As Paula Murray, Project Coordinator of San Diego's Viral Hepatitis Integration Program, explains, "It is one stop shopping for the client, and it makes sense from a customer service perspective." The

Other information that the program staff has learned from years of testing clients for hepatitis C is that clients do not always reveal an injecting drug use history or may have forgotten an experience years ago. Dr. Robert A. Gunn, Program Director, has documented that 40% of persons infected with hepatitis C virus (HCV) who did not report an IDU history prior to testing, later revealed such a history once they learned they were HCV positive (data submitted for publication). It was also determined that persons reporting "sex with an IDU" have an increased risk of HCV infection and such may be a good surrogate for risk. Murray recommends that clinics consider using this "risk factor" on risk assessments to capture individuals who may be reluctant to admit their own use of injection drugs.

Challenges for San Diego's viral hepatitis pro-

gram include meeting the follow-up medical evaluation needs of the clients who access public health clinics. Many such clients have no or limited access to services, no private insurance (a recent survey from the San Diego STD Clinic showed private insurance and do only 37% had any coverage at all), and do not qualify for any government assistance programs. The majority of these persons are males between the ages of 24 and 45 years. San Diego is also exploring the possibility of developing a public funding program,

> For more information, contact Paula Murray at pmurrahe@co.san-diego.ca.us or 619-692-8003.

such as HIV's Ryan White Care Act program,

to finance treatment for indigent clients.

Integrating Viral Hepatitis
Services into HIV and STD
Clinics:
Some Common
Themes

The previous profiles illustrate that integrating viral hepatitis services into existing clinics is a realistic and achievable goal. Although the six profiled sites vary in how they developed their program and in the scope of services they offer, they all share several key elements which helped facilitate successful programs, including:

#### KEY STAKEHOLDER INVOLVEMENT

Key stakeholders will likely include representatives from various departments at the clinic, including medical providers, counselors, laboratory staff, and front desk personnel. Involving all members that will be affected by the inclusion of additional services will help secure their buyin and investment in ensuring a smooth integration.

#### **TRAINING**

Providing extensive training to counselors and providers responsible for educating clients about viral hepatitis will help ease any discomfort they may feel about offering new services. Persons working in HIV and STD settings may know little about the different types of viral hepatitis and about vaccine, or how viral hepatitis prevention messages can be incorporated into existing HIV/STD prevention messages. Providing answers to their questions and offering ongoing educational sessions will help ensure that they feel comfortable delivering services. Developing a viral hepatitis curriculum for counselors and testers can further support integration.

#### **CAREFULLY ASSESSED RISK**

In order to ensure that limited viral hepatitis services are targeted to at-risk clients, it is necessary to utilize a risk assessment form that effectively captures client risk behaviors. If you find that clients are not identifying risks,

adapt your risk assessment based on information garnered during post-test interviews with persons testing positive for HCV who at pre-test did not indicate risk behaviors for HCV. The wording of the risks may limit the capture of risk behaviors. For example, clients may not identify as an injection drug user although they may have injected drugs once, so a risk assessment that asks whether "you have injected drugs, even only once" may be more successful in gaining client information than one simply asking whether "you have injected drugs." Similarly, some clinics have found that clients may more readily admit to "sex with and IDU" versus individual use of injection drugs.

#### **DATA COLLECTION**

It is critical to collect data on clients seeking and accessing viral hepatitis services in order to answer a range of questions. Data collection can help elucidate a number of questions, from the demographics of clients seeking services to the prevalence of HCV in your community. Data collection can help monitor the effectiveness of services offered and provide a rationale for funding.

#### TAILORED OUTREACH

Publicize and promote hepatitis services to the targeted population so that the appropriate persons access services. HCV tests and HAV and HBV vaccine are limited; these services simply cannot be offered to every person due to the scarcity of these resources. It is critical to target outreach to at-risk populations so that the "worried well" do not seek services.

## Integrating Viral Hepatitis Services Improved HIV and STD Prevention

Integrating viral hepatitis services into HIV and STD prevention services is increasingly recommended by a number of public health sources. In April 2002 the Directors of CDC's National Center for HIV, STD, and TB Prevention (NCHSTP), National Center for Infectious Diseases (NCID), National Immunization Program (NIP) and the Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Substance Abuse Treatment (CSAT) issued a letter stating: "Integration of hepatitis A and B immunization services into corrections and substance abuse treatment facilities and STD and HIV prevention programs is good public health practice and should be implemented wherever feasible." In May 2002 CDC released updated guidelines for the treatment of patients who have sexually transmitted diseases. The new guidelines highlight the need to immunize adults at risk for hepatitis A and hepatitis B, stating that men who have sex with men (MSM) who are sexually active should be screened annually for HIV, chlamydia, syphilis and gonorrhea and should be vaccinated against hepatitis A and hepatitis B. Disparate public health programs are increasingly recognizing the value of integrating disease prevention programs to positively impact the overall health of high-risk populations.

Further, while offering viral hepatitis services in HIV and STD clinic settings results in obvious benefits such as providing client-centered services and practicing sound public health, HIV and STD clinics anecdotally report that by offering viral hepatitis services they have been able to access high risk populations whom they believe would not otherwise seek clinic services. If viral hepatitis services are indeed serving as an "incentive" for populations to access clinics that can then provide HIV and STD pre-

Integrating Viral Hepatitis Services into Existing HIV and STD Clinics

vention services, offering integrated services is of significant importance to HIV and STD prevention. Recent data revealing a high rate of unrecognized HIV infection among young black MSM² and of increasing rates of syphilis among MSM³ indicate that certain high-risk populations are not accessing HIV and STD prevention services. Whether viral hepatitis services have the potential to attract high-risk populations who may not be accessing STD and HIV prevention services is a question not yet answered. However, it is clear that HIV, STDs, and viral hepatitis are converging epidemics affecting the same populations, and integrated disease prevention programs will undoubtedly benefit populations at risk.

### References

<sup>1</sup>Centers for Disease Control and Prevention (CDC). Hepatitis B Vaccination Among High-Risk Adolescents and Adults – San Diego, California, 1998-2001. *Morbidity and Mortality Weekly Report*, 2002: 51(28): 618-621. Available online at:

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<sup>2</sup>Centers for Disease Control and Prevention (CDC). Unrecognized HIV Infection, Risk Behaviors, and Perceptions of Risk Among Young Black Men Who Have Sex with Men – Six U.S. Cities, 1994-1998. *Morbidity and Mortality Weekly Report*, 2002: 51(33): 733-736. Available online at:

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<sup>3</sup>Centers for Disease Control and Prevention (CDC). Primary and Secondary Syphilis Among Men Who Have Sex with Men – New York City, 2001. *Morbidity and Mortality Weekly Report*, 2002: 51(38): 853-856. Available online at:

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# Viral Hepatitis and Injection Drug Users

## Viral Hepatitis and Injection Drug Users

ore than two decades into the HIV/AIDS epidemic, there are few Americans who are not aware of the severity of this public health problem and cannot identify the major risk behaviors associated with HIV-unprotected sex and injection drug use. Fewer Americans are aware of the threat of viral hepatitis, even though viral hepatitis affects millions, can cause serious illness, and overlaps with the HIV/AIDS epidemic.

Due to similar transmission routes, many of the populations at risk for HIV are also at risk for viral hepatitis. For both HIV and viral hepatitis, injection drug users (IDUs) are an important target population. One-third of all cases of AIDS are directly or indirectly attributed to injection drug use, and approximately 60 percent of persons infected with hepatitis C virus (HCV) report injection drug use as the risk.

Reaching those at risk or already infected with HCV is a public health imperative. HCV is much easier to transmit that HIV. HCV can be passed on by using injection equipment, not just a syringe, that has come in contact with an infected person's blood. And while the science is still inconclusive, the HCV virus may survive for several days or longer on drug paraphernalia and other surfaces. If any equipment is re-used without adequate cleaning, it may contain blood that can infect the next person using that equipment. HIV is a much more fragile virus, making transmission more difficult. HCV is also rapidly acquired after the initiation of injection; the majority (an estimated 50 to 80 percent) of IDUs who have been using drugs for more than five years are infected with HCV.

As with HIV, identifying HCV-infected individuals provides opportunities to improve their health. HCV-infected IDUs can be offered drug treatment and encouraged to take steps that can delay the onset of disease. For those who continue to use drugs, they can be taught to inject more safely and reduce the possibility of infecting others.

Because of the HIV/HCV overlap, integrating prevention efforts is an obvious strategy for reaching at-risk individuals. However, many HIV prevention programs have yet to incorporate hepatitis prevention messages into their overall education efforts. Fewer programs offer screening for hepatitis and referral to hepatitis-related services. While resources for hepatitis services are extremely limited, it is possible to provide services through integration with HIV, STD or substance abuse prevention and treatment programs by building on their existing ties with at-risk populations.

This report is designed to provide information on a variety of topics related to viral hepatitis and IDUs, with the intention of promoting an understanding of the issues related to serving this at-risk population. Included in the report is:

- Information on injection drug use, viral hepatitis and HIV and the relationship between these conditions:
- Interventions available for IDUs, such as drug treatment, outreach, and syringe availability, that provide an opportunity to integrate hepatitis-related services;
- Strategies for preventing blood-borne infections in IDUs that can be incorporated into programs targeting this population;
- Services for IDUs infected with hepatitis B virus (HBV) and HCV (beyond clinical care); and
- Profiles of successful integration efforts.

#### DEFINING THE CHALLENGE: INJECTION DRUG USE, VIRAL HEPATITIS AND HIV

#### Injection Drug Use

While it is difficult to identify the actual number of injection drug users (IDUs), primarily because of the illegal nature of this activity, there are an estimated 1 million active users of injection drugs in the United States. In addition to heroin, cocaine and amphetamines are also injected by drug users.

During the 1990s, heroin use increased after declining for many years. However, recent research suggests that more heroin users are smoking or sniffing the drug instead

## **GENERAL Health Issues for IDUs**

In addition to blood-borne infections, there are myriad health problems associated with injection drug use. These can occur as a result of a single drug-using episode, such as an overdose, or from the cumulative effects of drug use.

**Overdose** can occur when too much of the drug is taken and it overwhelms the body, effecting the brain, lungs, heart, liver, and kidneys. Overdoses can result in death. The drug Naloxone (also known as Narcan), which reverses the effect of an opiate, can revive people who have overdosed on heroin. Some advocates for drug users support making it available without a prescription so drug users have access to it when necessary. Organizations serving drug users also work to educate them about overdose prevention and how to help someone who has overdosed, such as through the provision of CPR and other measures. However, fear of legal consequences can prevent people from seeking help in the event of an overdose.

**Injection-related wounds and infections** can occur, even with efforts to inject in a safe manner. Abscesses are common, and in rare occasions can result in sepsis, endocarditis, amputation or death. Other infections, such as necrotizing soft tissue infection (also known as flesh eating bacteria), wound botulism, and wound tetanus can occur.

IDUs should be educated about and encouraged to use safer injection techniques. In addition, they should learn danger signs associated with these health issues and know when to seek care. Adopting safer ingestion methods, such as snorting or smoking, can prevent these injection-associated conditions.

of injecting. The purity of heroin now available on the street makes smoking and sniffing an attractive alternative for users.

It is estimated that, each year, 13 to 16 million Americans could benefit from substance abuse treatment (both alcohol and drug treatment). Unfortunately, only 3 million receive treatment each year. Those in need of treatment are a highly diverse population, necessitating a wide variety of approaches tailored to various needs. No single approach is appropriate.

Those seeking treatment encounter many barriers. These include lack of access to treatment locations (no transportation), lack of knowledge about available treatment, inability to pay for treatment, cumbersome enrollment processes, and waiting lists. The decision to seek treatment on the part of a drug user may signify the start of a long, arduous process.

While injectors are the primary target of interventions designed to prevent the transmission of blood-borne infections, it is also important to target prevention efforts to drug users who are not yet injecting. Some research indicates that use of non-injected drugs, especially when initiated at an early age, can lead to the use of other drugs. Preventing at-risk

youth from initiating drug use, or providing drug treatment to young people already using drugs, can prevent them from progressing to more serious drugs, including those that are injected.

#### Viral Hepatitis

Viral hepatitis is the name collectively used for liver infections caused by five major recognized types of hepatitis viruses (A, B, C, D, and E). These viruses – known respectively as HAV, HBV, HCV, HDV, and HEV – may cause acute illness, as well as chronic infection, posing the risk of long-term, negative health outcomes including cirrhosis, liver failure, and liver cancer.

 HAV is transmitted through fecal-oral contact with an infected person, causes acute infection only, and is vaccine preventable. In 2001 there were an estimated 93,000 total HAV infections. Typically, about half of all infections are symptomatic and about 100 cases lead to death.

#### HIV

HIV is at the forefront of the public's consciousness when it comes to discussions about risks associated with injection drug use. As of December 2001, there were 506,154 people reported living with HIV/AIDS in the U.S. The cumulative number of AIDS cases reported to CDC as of December 2001 is 816,149, of which 467,910 have died. Adult and adolescent AIDS cases total 807,075 with 666,026 cases in males and 141,048 cases in females. Through the same time period, 9,074 AIDS cases were reported in children under age 13.

In the U.S., over one-third of AIDS cases are directly or indirectly related to injection drug use, including sex with a drug user or perinatally through an infected mother with either a history of drug use or sex with a drug user. IDU-related HIV/AIDS remains disproportionately high among African American, Native American/Alaskan Native, and Hispanic men compared to white men.

- HBV is transmitted through contact with the blood or body fluids of an infected person and can result in chronic infection. About 6 percent of persons infected with HBV over the age of 5 years develop chronic infection. It is estimated that 1 to 1.25 million Americans have chronic HBV infection, slightly less than .5 percent of the U.S. population, and there were an estimated 78,000 new HBV infections in 2001. There is a vaccine available to prevent HBV infection.
- HCV is transmitted largely through contact with the blood of an infected person and 75 to 85 percent of those infected develop chronic infection. An estimated 2.7 million Americans are chronically infected with HCV and, in 2001, there were approximately 25,000

new cases. Liver disease develops among 70 percent of those chronically infected with HCV, leading to cirrhosis in about 15 percent (developed over 20 to 30 years) and death among 5 percent – some 8,000 to 10,000 deaths annually. Chronic HCV infection is a leading indicator for liver transplantation. There is no vaccine for HCV.

 HDV is a defective virus that requires the helper function of HBV to replicate. HDV may occur either as a co-infection (being transmitted at the same time

Outcome	HAV	HBV	HCV	HIV	STD*
<b>Chronic Infections</b>	n/a	~1.25 million	~2.7 million	~0.8 million	n/a
New Infections/yr	~93,000	~78,000	~25,000	~40,000	`1.1 million
Deaths/vr	100	5.000	8.000	18,000	

**TABLE 1** Estimated Disease Burden of HAV, HBV, HCV, HIV Infections and other STDs in the U.S. in 2001. \*Chlamydia (255/100,000 population) and gonorrhea (150/100,000) in 2000 Source Centers for Disease Control

as HBV) or as a super-infection (being transmitted to a person who already has chronic HBV infection). HDV is transmitted in many of the same ways as HBV, although it appears rarely to be transmitted from mother to baby. Vaccination against HBV is the best prevention for HDV infection. Persons who are chronically infected with HBV must continue to practice HBV preventive-behaviors in order to reduce their risk of HDV infection.

 HEV is transmitted through water contaminated with fecal matter. It is rare in the U.S., occurring among some travelers newly returned from areas where HEV is endemic, particularly Mexico, parts of Africa, China, and other parts of Central, South and East Asia. The best way to avoid HEV is by drinking only bottled water and not eating uncooked food when visiting affected regions.

#### Hepatitis and HIV

#### in Injection Drug Users

In 2000, an estimated 60 percent of the new cases of HCV infection and 17 percent of the new cases of HBV infection occurred in drug users. HBV and HCV are transmitted very efficiently through blood exposure and infection occurs more rapidly than with some other blood-borne viruses, including HIV. Within five years of initiating injection drug use, 50 to 70 percent of IDUs will be infected with HBV and 50 to 80 percent will be infected with HCV. Because HIV, HBV and HCV are all transmitted through contact with an infected person's blood, IDUs are highly susceptible. An estimated 50 to 90 percent of persons infected with HIV through IDU area also infected with HCV. No studies have yet described the prevalence of HBV infection in a nationally representative HIV patient cohort.

Research indicates that co-infection with HIV and HCV results in higher levels of HCV in the blood, more rapid progression to HCV-related liver disease, and increased

#### What is Addictphobia?

There is a profound stigma attached to illegal drug use--and injection drug use in particular. This stigma affects how people perceive drug users as individuals and how society addresses the challenges presented by drug addiction. At the 1999 National HIV Prevention Conference, T. Stephen Jones, MD, of CDC's Division of HIV/AIDS Prevention, and Terje Anderson, Executive Director of the National Association of People With AIDS, presented the concept of "junkiephobia" or "addictphobia." The terms describe the "complex of stereotypes, stigmas, and negative attitudes" that affect how the public, policymakers, health care professionals, and drug users themselves view those who are addicted to drugs. These attitudes influence public policy and society's sympathies, deterring the implementation of interventions needed to prevent hepatitis and HIV and limiting resources needed to increase access to drug treatment. Four negative stereotypes associated with drug users were identified:

- Drug users are believed to be criminals and their addiction represents a moral failing that should be punished rather than treated;
- Drug users are unwilling or unable to change their risk behaviors;
- Drug users are unreliable participants in clinical trials; and
- Drug users are unable to adhere to complicated treatment regimens.

Professionals working with drug users are not immune to these negative attitudes and drug users may not receive the same care as those not using drugs. For example, the 1997 NIH Consensus Statement on the Management of Hepatitis C (HCV) recommended that persons who use illicit drugs should not be treated for HCV until they have abstained from drug use for a minimum of six months. After criticism from researchers, medical providers, and advocates, the guidelines were revised in 2002 and now recommend that treatment decisions be made on a case by case basis.

risk for cirrhosis and liver cancer. HCV is considered an opportunistic infection in people with HIV infection, but it is not an AIDS-defining illness. The effects of HCV on HIV are less well understood. Some research suggests that infection with certain genotypes of HCV, genotype 1 in particular, is associated with more rapid progression to AIDS or death. There is also some evidence to suggest that HCV is associated with impaired CD4+ T cell recovery during antiretroviral therapy. The impact of HBV on HIV infection is unclear.

Treatment for both HCV and HIV infection is complicated, expensive, and has side effects, which can affect the quality of life of individuals who are co-infected. Traditionally, HIV and hepatitis have been treated by physicians representing different medical specialties. The complexities of both diseases demand that infectious disease physicians and hepatologists work together to treat those who are co-infected. Clinics, jointly managed by an HIV specialist and hepatologist and supported by substance abuse and other mental health providers, may be the most effective response.

Providing medical care to IDUs can be a challenge. There are additional conditions, such as mental illness, ongoing substance use and alcoholism, which affect this population. In addition, many IDUs have unstable living situations. Finally, IDUs, in part due to the stigma associated with the use of illegal drugs, are a highly marginalized population and may have little contact

with, and strong suspicion of, health care providers. This can affect their willingness to seek treatment and their adherence to treatment once they enter care.

#### **Understanding Addiction**

To effectively reach IDUs with hepatitis and HIV prevention efforts, it is necessary to understand the context in which they live and the nature of addiction. In the U.S., addiction has traditionally been viewed as a moral failing or weakness. However, research indicates that addiction is a brain disease and that repeated drug use over time changes the structure and function of the brain. These changes remain long after the individual stops using drugs. While these biological changes are significant, they are not the sole cause of addiction. There is also a behavioral aspect to addiction. Individuals may find drug use to be a pleasurable experience and repeat use until addiction occurs. Or, they may suffer from a co-occurring mental illness, as do approximately half of all drug users. In the case of co-occurring mental illness, the use of drugs may be an attempt to self-medicate.

Research conducted by the National Institute on Drug Abuse (NIDA) indicates that drug abuse is preventable, in that it begins as a voluntary behavior, and drug addiction is a treatable disease. While it is treatable, successful treatment can be a challenge. Misconceptions about drug treatment abound. For example, many believe that drug users can stop using drugs on their own, without treatment, and that most drug users can become permanently drugfree. These viewpoints are often based on the perception that ongoing drug use is voluntary on the part of an addict and that an addict's inability to overcome addiction stems from a lack of willpower. Drug addiction is a chronic, recurring, illness and relapses after treatment are normal.

Because of the powerful biological and behavioral dimensions of addiction, most IDUs cannot quit on their own. Drug treatment can provide the medical, psychological, and behavioral support that drug users need to overcome their addiction. However, for most drug users, treatment is a long-term process involving multiple interventions and attempts at abstinence. This is not to say that drug users are less successful in their effort to get healthy than people suffering from other conditions. Drug treatment is as effective as treatment for other chronic conditions, including diabetes, hypertension, and asthma.

## Key Elements of Successful Treatment

- Readily available
- Provided for an adequate length of time
- Multiple treatment episodes as required
- Takes co-morbidities into consideration
- Tailored to individual characteristics and needs
- Periodic adjustments to treatment approach as needed

#### INTERVENTIONS AVAILABLE FOR IDUS

The various services targeting IDUs that are currently carried out provide an opportunity to integrate hepatitis prevention messages and services. Many of the services described below offer a "point of access" to IDUs. IDUs are known as a "hard-to-reach" population. Taking advantage of any contact with IDUs to impart necessary health promotion messages is considered an effective approach to engaging this population in health care. For example, when approached by an HIV prevention outreach worker, an IDU may be primarily interested in drug treatment. If that outreach worker can refer the IDU to drug treatment, this first step may lead to the IDU receiving HIV counseling and testing, and if positive, HIV care. This same integration process can be applied to hepatitis services.

#### **Substance Abuse Treatment**

Comprehensive and ongoing substance abuse treatment can help a person who is addicted to reduce or stop using drugs. Substance abuse treatment is conducted in a variety of settings, such as inpatient, outpatient, or residential, and often involves multiple approaches, including behavioral therapy, medications, or a combination of both. In addition, some comprehensive programs also work to meet the wider needs of their clients and offer referral to other services. There are also specialized programs designed to address the needs of specific populations such as women with children, young people, incarcerated individuals, or gay men and lesbians.

#### **Medication-Assisted Treatment**

Medication-assisted treatment (MAT) is a form of treatment where opiate-dependent patients receive medication to block the effects of opiates. There are four medications used to treat opiate addiction: Levo-alpha-acetylmeth-adol (LAAM), naltrexone, buprenorphine, and methadone. Methadone, the most commonly used medication, is a synthetic opiate that prevents withdrawal symptoms, decreases cravings, and blocks the euphoric effects of opiates. It is usually administered once per day. Methadone maintenance treatment (MMT) has been used for over 30 years as an effective medication-assisted treatment for opiate addiction. Research has found that MMT reduces

#### HARM REDUCTION AND DRUG USE

Harm reduction is a concept that recognizes abstinence as the optimal outcome while promoting alternatives that reduce the harm associated with a behavior. According to the Harm Reduction Coalition, harm reduction is a set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use, to managed use, to abstinence. Many of the services described in the following section embrace the concept of harm reduction to various degrees. However, there are some service providers that do not support this concept. These providers tend to view drug treatment focusing on abstinence as the only appropriate service for drug users.

The Harm Reduction Coalition has identified the following key principles relating to harm reduction.

- Licit and illicit drug use is a reality and efforts should be made to minimize the harmful effects of drug use rather than to ignore or condemn them.
- Drug use is a complex, multi-faceted phenomenon that encompasses a continuum of behaviors from severe abuse to total abstinence, and some ways of using drugs are safer.
- Quality of individual and community life and well-being--not necessarily cessation of all drug use--are the criteria for successful interventions and policies.
- Non-judgmental, non-coercive provision of services and resources should be provided to drug users and the communities in which they live in order to assist them in reducing related harm.
- Drug users and those with a history of drug use should routinely have a voice in the creation of programs and policies designed to serve them.
- Drugs users, as the primary agents of reducing the harm of their drug use, should be empowered
  to share information and support each other in strategies that meet their actual conditions of
  use.
- The realities of poverty, class, racism, social isolation, past trauma, sex-based discrimination and other social inequalities affect both people's vulnerability to and capacity for effectively dealing with drug-related harm.
- The real and tragic harm and danger associated with licit and illicit drug use should not be minimized or ignored.

Harm reduction strategies should meet drug users "where they are at," addressing conditions of use along with the use itself. Harm reduction programs are characterized by the provision of client-centered, non-judgmental, and culturally appropriate services that can be easily accessed by clients. These programs emphasize client-determined goals and behavior change. Harm reduction-based interventions and policies for drug users should reflect specific individual and community needs--there is no universal definition of or formula for implementing harm reduction. Harm reduction programs in the United States carry out various services and activities, based on the needs within their communities. These include:

- Educational activities designed to promote safer injection practices and help drug users make safer choices;
- Provision of sterile syringes and paraphernalia (cookers, cotton, etc.) to allow for safer injection (some programs do not provide sterile syringes but provide bleach for the cleaning of syringes);
- Advocacy to promote policy change, such as laws that make sterile syringes more readily available;
- Links to drug treatment or other health or social services that drug users might need;
- Overdose prevention education efforts; and
- Promotion of less risky ways to administer drugs, such as snorting or smoking heroin instead of injecting it.

More information on harm reduction is available from the Harm Reduction Coalition at http://www.harmreduction.org.

crime, improves health status, and helps opiate-dependent individuals attain productive lifestyles. It also significantly reduces the health risks associated with injection drug use.

The success of MMT may depend on the adequacy of dosage and the continuity of treatment. A minimum of one year is recommended by current National Institutes of Health guidelines and most patients require continuous treatment over many years or even life. MMT is more effective when coupled with psychiatric and counseling services, due to the high co-morbidity of addiction and mental health disorders. Until recently, methadone was only available in specially licensed clinics with strict requirements. Consequently, these clinics had little flexibility in providing individualized treatment, and patients were often not given adequate doses.

Methadone is controversial. Critics argue that MMT replaces one drug with another. There has also been a strong "not in my backyard" sentiment towards methadone clinics, driven by the fear that the clinic will bring crime and drugs to the neighborhood. The relaxing of the regulations on methadone may help reduce some of this stigma.

Buprenorphine, which became available in 2002, is also used to treat heroin and other opioid dependence. Buprenorphine is related to morphine and functions on the same brain receptors, but does not produce the same high, dependence or withdrawal syndrome. It is long-lasting and well-tolerated by addicts.

Buprenorphine is used by physicians in office-based treatment, as long as they obtain the required training and a waiver that allows them to prescribe certain controlled substances. Physicians must also refer patients to care for their social and psychological needs. This new treatment option allows patients to be treated for addictions in the same manner as they are treated for other chronic illnesses, such as diabetes or hypertension.

#### Outreach

Community-based outreach activities are part of a comprehensive prevention approach that includes a variety of complementary components, such as drug treatment

## ATTITUDES OF HIV AND SUBSTANCE ABUSE PROVIDERS

IDUs may require a broad range of services, such as drug treatment, HIV services, and other social services (housing, legal, etc.). However, these various service providers may not have a history of working together and the professionals who provide these services vary in their training, experience, attitudes, and approaches. This has served as an impediment to the integration of the services required by IDUs, especially coordination between HIV services and drug treatment.

At the heart of these differences is the attitude of the providers toward ongoing drug use and abstinence. Most substance abuse treatment models focus exclusively on abstinence as the only acceptable short- and long-term treatment outcome. Individuals in treatment programs who continue to use drugs are often required to leave the program. In contrast, HIV service providers tend to take an approach of treating the individual "where they are at" and may prioritize health care and other services such as housing, above drug treatment. HIV service providers work very hard to avoid "losing a patient to care" and case managers go to great lengths to continually engage clients, whether they are using drugs or not. Also, HIV risk reduction messages that emphasize safer injection practices may seem to be contradictory to drug treatment providers and appear to undermine their efforts. Providers who seek to integrate HIV prevention into drug treatment, or link HIV care to drug treatment need to reconcile these conflicts.

While this conflict has become less of a challenge over the years, drug treatment providers have also been reluctant to address HIV because it can complicate the treatment process. IDUs trying to cope with their HIV diagnosis may not be able to focus on their addiction and they may have issues that drug treatment providers are unable to address. This is especially true for treatment programs that included group therapy. In response, some drug treatment programs have been developed specifically for people living with HIV.

In addition to the differences related to abstinence and the challenges of addressing both conditions, providers in drug treatment and HIV services may have limited knowledge of other services and may not have received training beyond their own discipline. Cross-training has proven to be a very effective approach in bridging the gaps between providers. Cross-training of staff from HIV services, substance abuse, primary care and other social services allows professionals to learn about other service approaches, create linkages and facilitate dialogue across disciplines. HIV prevention workers can gain a greater appreciation for the challenges of drug treatment and drug treatment providers can become more comfortable with the screening, risk assessment, and harm reduction skills key to HIV and hepatitis prevention activities. All providers can improve their ability to respond to the overlapping health and behavior problems of IDUs seeking services.

Key to the success of cross-training initiatives is the support of high-level administrators. Their participation and support can encourage acceptance, break down the barriers, and ensure that the cross-training is institutionalized and available on an ongoing basis.

In 1993, the federal Center for Substance Abuse Treatment (CSAT) and CDC developed an interagency initiative to provide cross-training workshops across the country. In 1998, the Health Resources and Services Administration (HRSA) joined the initiative.

Finally, there are some legal barriers to collaboration. Federal confidentiality protections prohibit drug treatment staff from sharing information about patients with public health staff. These can be addressed through the development of qualified service organization agreements (QSOAs), which are interagency agreements that allow drug treatment and public health providers to share some information about patients within the legal constraints of federal confidentiality protections.

and sterile syringe access programs, to help IDUs increase their protective behaviors and reduce their risks for HIV, HBV, HCV, and other sexually transmitted diseases (STDs).

Community-based outreach workers are often the first contact between IDUs and service providers. Because they are responsible for taking prevention messages to IDUs, it is important that outreach workers know where, when, and how to contact IDUs within their own environment. A good outreach worker becomes a trusted and recognized source of information for the target

population. In addition to prevention messages outreach workers can also serve as a bridge to treatment, counseling and testing or other services. Some outreach workers distribute condoms, bleach kits, sterile syringes

and other materials that allow IDUs to

reduce their risk.

## Community-Based Outreach Model

The National Institute on Drug Abuse (NIDA) has developed a manual that discusses the principles of HIV prevention for drug users and their sex partners, including step-by-step instructions for conducting community-based outreach. It also includes information for program managers to use in designing outreach risk reduction programs in their communities.

The model includes two interrelated components designed to facilitate behavior change among at-risk drug users. These include: 1) community-based outreach conducted in a range of local settings to access and engage drug users in the process of behavior change to prevent HIV and other blood-borne infections; and 2) education and risk reduction sessions organized around HIV, HBV, and HCV testing to provide pre- and post-test counseling to help drug users learn about their serostatus and the behavior changes needed to reduce transmission risks.

The NIDA Community-Based Outreach Model: A Manual to Reduce the Risk of HIV and Other Blood-Borne Infections in Drug Users is available at http://drugabuse.gov/CBO/index.html.

Indigenous, or peer, outreach workers can be especially effective. They know, and are known in, the community and may have easier access to the target population. Outreach workers with a history of drug use may have more credibility with the target population because they have "been there and done that." They can honestly discuss drug use, the challenges of treatment, and the benefits of getting clean. By being in the community and regularly available, they can help the target population on their own terms and be there when a drug user decides he or she is ready for help. It is important that outreach workers who are former drug users be provided appropriate support to help them stay clean. Immersing themselves in an

environment where drug use is prevalent can put them at risk of relapse.

Outreach is not only appropriate for urban areas. However, it can be a challenge in other settings. In some ways, outreach is more necessary in rural or semi rural areas.

In these settings, drug users are more isolated and more concerned with confidentiality. In a community where everyone knows everyone, people may be reluctant to disclose their drug use to anyone. If there is a service provider available, IDUs may not want to be seen visiting the office since it could lead to speculation on the part of their neighbors. In rural areas, outreach workers must be creative. For example, an outreach worker may rely heavily on telephone contact and pre-arranged meetings with clients, either at their homes or specific, neutral locations.

Within the population of IDUs there are many subpopulations that may require specialized outreach. These include incarcerated individuals, sex workers, and youth. Because of the unique aspects of these populations, peer outreach workers can be especially effective.

#### Syringe Access

Use of sterile syringes greatly reduces the risk of infection for IDUs. Unfortunately, sterile syringes are not readily available to many IDUs, for a variety of reasons. Advocates for harm reduction view increasing the availability of sterile syringes as one of the most important ways to reduce the spread of blood-borne infections.

When they are not readily available, IDUs must obtain their syringes from drug dealers, needle dealers, in shooting galleries, or from friends and injection partners. Some IDUs are able to obtain syringes from diabetics, who have access to syringes. Many of the syringes obtained through these methods have been used before and are contaminated.

Why are sterile syringes so hard to obtain? In most part, it is due to policies designed to limit access in the belief that it will reduce drug use. Most states have legal restrictions on the sale and distribution of sterile syringes, in the form of drug paraphernalia laws and syringe prescription laws. These restrictions create barriers to various syringe availability strategies, which are listed below.

 SYRINGE EXCHANGE PROGRAMS (SEPS) provide IDUs with free sterile syringes. Since clients

## New York State's Expanded Syringe Access Demonstration Program (ESAP)

In 2000, amendments to the New York State (NYS) Public Health Law established the Expanded Syringe Access Demonstration Program (ESAP), which became effective January 1, 2001. ESAP allows for licensed pharmacies, health care facilities and health care providers who can otherwise prescribe hypodermic needles or syringes to register with the NYS Health Department to sell or furnish up to 10 hypodermic needles or syringes to persons 18 years of age or older, without a prescription. This change in the law gives adults access to sterile syringes from a reliable source without a prescription. One of the requirements of ESAP is that each time syringes are sold or furnished under the program, a "safety insert" is included, which explains proper syringe use, safe disposal, risk of blood borne diseases, dangers of injection drug use, how to access drug treatment and information about HIV/AIDS.

While ESAP's primary focus is on enhancing syringe access through nonprescription pharmacy sales, provisions concerning safe disposal were included. To qualify for registration to sell or furnish syringes under ESAP, eligible providers must "cooperate in safe disposal of used hypodermic needles and syringes." NYSDOH developed "New York State Guidelines for Pharmacies Interested in Accepting Hypodermic Needles, Syringes and Other 'Sharps' Used Outside of Health Care Settings for Safe Disposal (March, 2002)" to assist pharmacies. These guidelines can be viewed online at http://www.heath.state.ny.us/nysdoh/hivaids/esap/pharmdispose.htm. Further, NYSDOH is pursuing community sharps collection and disposal through community-based syringe access and safe disposal demonstration projects. Coalitions reflecting numerous partners and perspectives are exploring options, including placement of sharps collection "kiosks" in convenient settings, such as pharmacies, clinics and communitybased organizations. Syringe exchange programs (SEPs) are forging new partnerships with pharmacies to "close the loop" by offering sharps containers and information about the SEPs as resources for safe disposal. The NYC DOH has installed "drop boxes" outside of public clinics in all five boroughs of NYC to offer new options for safe disposal. Collection of household sharps has been facilitated through development of the "New York State Safe Sharps Collection Program". A registration form is available on the NYSDOH website at http://www.health.state.ny.us/nysdoh/hivaids/ esap/pdfs/sharpscoll.pdf. ESAP has provided impetus for these and other safe disposal initiatives.

An independent evaluation conducted in consultation with the NYS AIDS Advisory Council was submitted to the Governor and the Legislature on January 15, 2003 that assessed the impact of ESAP on needle and syringe sharing, substance abuse, pharmacy practice, criminal activity, accidental needlesticks among law enforcement, sanitation and other personnel, syringe disposal and various methods of education on safe use and proper disposal. Results of this evaluation were considered when the Governor and Legislature extended ESAP through September 1, 2007.

For more information about ESAP, please visit http://www.health.state.ny.us/nysdoh/hivaids/esap/regover.htm.

must bring in used syringes to "exchange," the programs do not increase the number of syringes in circulation or create a problem with discarded syringes. Many SEPs serve as a bridge to other services and can link clients to substance abuse treatment, education and counseling, and health services.

- PHARMACY SALES allow IDUs to purchase sterile syringes. However, over 20 states have pharmacy regulations or practice guidelines that limit the pharmacy sale of sterile syringes to IDUs. These regulations, which can require purchasers to show identification, sign a register of syringe purchasers, or state the purpose for the purchase, can serve as a significant deterrent to IDUs who are reluctant to provide personal information due to the illegal nature of the activity. Even if there are no legal barriers to purchase, individual pharmacies or staff can take steps to discourage IDUs from patronizing their establishment. To expand this option, policy changes are required to abolish restrictions and efforts are necessary to educate pharmacists about the medical imperative of increasing access to sterile syringes.
- PHYSICIAN PRESCRIPTION is also a way to increase syringe availability. Some IDUs may feel more comfortable working with their physician to address their addiction. Taking the steps to initiate safer injection practices,

and obtaining a prescription from their physician, can be a first step in overcoming addiction. While this approach is probably appropriate for only a small segment of the drug using population, it does increase the options available to drug users.

All three of these options serve to increase the availability of syringes. Supporters of syringe access stress the importance of multiple options that can meet the needs of various drug users. For example, an IDU may not have money to purchase syringes from a pharmacy and may rely on free syringes from a SEP. Another IDU may be most comfortable obtaining a prescription from their physician in order to give a certain feel of legitimacy to the purchase.

The question of syringe disposal must be addressed simultaneously with syringe access. Improper disposal of syringes presents a threat to public health. In many community- level debates about syringe access, fear of increased numbers of used syringes discarded on the street, playgrounds, or other public places becomes a major issue. Drug paraphernalia laws can serve as a barrier to safe disposal of syringes. These laws often criminalize possession of syringes. Since they risk arrest, IDUs may be more likely to discard a syringe in an unsafe manner instead of keeping it in their possession until they can dispose of it safely.

Supporters of syringe access argue that their efforts encourage the safe disposal of syringes. With exchange programs, used syringes become a valuable commodity. In some communities, the establishment of a SEP reduced the number of used syringes found on the street. Physicians and pharmacists can discuss proper disposal with their clients and provide sharps containers. Some communities have installed drop boxes or established drop off sites for safe disposal. For information on safe community needle disposal, visit http://www.safeneedledisposal.org.

To access a series of fact sheets on syringe access and disposal, visit the CDC's website at http://www.cdc.gov/idu/facts/index.htm.

#### **Prevention Case Management**

Prevention case management (PCM) is an intensive intervention targeting people at risk of, or infected with, HIV. It is an ongoing, one-on-one intervention intended to meet the specific needs of the person at risk. For people who are not infected, the goal is to get them to adopt behaviors that keep them from becoming infected. For those who are already infected, the goal is to adopt behaviors to prevent transmission to others. Because PCM is designed for individuals with complex lives and circumstances, it is an especially appropriate intervention for IDUs who face various stigmas associated with drug use and often live in challenging situations.

The focus of PCM is to meet clients "where they are at" and help them to adopt lower risk behaviors. Some clients are linked with PCM after they are tested for HIV and, based on an assessment, are determined to be at risk. Others are reached through outreach activities. For these, the first step might be taking an HIV test to learn their status.

Ongoing support for behavioral change is a key element of PCM. Clients are educated on how to reduce their risk. In addition, clients are linked to other services. These services can include counseling to explore factors, such as a history of abuse, that lead to high-risk activities, or supportive services such as housing, employment or drug treatment. By treating all of a client's needs, that client can hopefully become healthier overall, and therefore more able to adopt lower-risk behaviors.

CDC has identified seven key components of PCM:

- · Client recruitment and engagement;
- Screening and comprehensive assessment of HIV and STD risks, medical and psychosocial service needs, including STD evaluation and treatment, and participation in drug treatment;
- Development of a client-centered prevention plan;
- HIV risk-reduction counseling over multiple sessions;
- Active coordination of services with follow-up;
- Monitoring and reassessment of clients' needs, risks, and progress; and
- Discharge from PCM when the client attains and maintains his or her risk-reduction goals.

#### **HIV Counseling and Testing**

HIV counseling and testing allows individuals to learn their HIV serostatus, receive individual, client-centered risk reduction counseling, and obtain referral to additional services in a private and confidential manner. Those testing HIV positive are referred to clinical care and case management and those who are not infected

receive counseling and support for risk reduction efforts and referrals to appropriate services.

#### **Beyond Sterile Syringes**

Because HCV is more infectious that HIV, messages designed to prevent the spread of HCV must focus on a broader range of activities than HIV prevention messages.

In addition to the use of a sterile syringe, HCV prevention messages must also encompass:

- Use of new or disinfected paraphernalia;
- Use of sterile water to prepare drugs;
- Dividing drugs before they are prepared for injection (not sharing drugs); and
- Sterilization of the surfaces where the drugs are prepared.

Bottom line, any contact with blood is risky. For example, if a drug user uses a piece of cloth to stop the bleeding after an injection that has been used by another drug user for the same purpose, even if it is days or weeks later, infection can occur.

It is important to note that expanded prevention messages present a challenge to educators. People can only absorb so much information in a single exchange and drug users may not, for a variety of reasons, be able to carry out all the necessary steps to ensure a safe injection. Because of these challenges, supporters of harm reduction stress the importance of moving drug users along a continuum toward safer behavior. Of course, cessation of drug use is the safest of all behaviors and promotion of drug treatment should always be a component of HIV and HCV prevention messages.

Because many IDUs mistrust conventional health service systems or have limited access, services should be provided in different venues, such as drug treatment facilities or during outreach activities, and delivered in a nonjudgemental manner. Recent innovations in HIV testing, such as rapid tests where results are provided in the same visit and oral fluid testing kits, which allow antibody testing without the need for a blood sample, may make testing more attractive to IDUs.

Despite its general availability, there are still a very large number of people who do not know their HIV status. Many people who are tested for HIV do not return for their results. Others, who learn that they are infected, do not seek additional services for a variety of reasons.

A serious implication for IDUs is that federally-funded HIV counseling and testing activities do not currently include counseling, testing and referral for other blood-borne infections like hepatitis B and hepatitis C. Offering these additional screening services would probably serve as a very strong incentive for IDUs.

## Safer Injection with the "One Hit Kit"

Positive Heath Project, Inc., an HIV prevention/harm reduction agency located in New York City, and Safety Works, a distributor of harm reduction program supplies, collaborated with researchers from the Yale University School of Public Health to develop and conduct a survey measuring perceived risk, injection behavior and HCV infection in IDUs. The goal of the study was to determine possible strategies to reduce the risk of HCV infection related to the use of drug injection equipment and to drug injecting practices. Three other syringe exchange programs from Los Angeles, Connecticut and Wisconsin participated in the study.

The study consisted of surveying clients of the participating syringe exchange programs in New York City, Los Angeles, Connecticut and Wisconsin. The study found that clients were less educated about HCV than HIV and believed that the risk reduction techniques they used for HIV would protect them against other bloodborne infections. The survey also found that clients were unaware of the dangers associated with the reuse or sharing of water (as soon as a used syringe is dipped into a water bottle, the water and bottle become contaminated and should no longer be used), of the importance of using clean paraphernalia, and of eliminating skin contact with blood.

To address and help change these risky injection practices, project collaborators created the "One Hit Kit." This kit contains one cooker, one cotton filter, one sealed 5 ml vial of water, one alcohol pad to clean the injection site and one gauze pad to stop the flow of blood from the injection site. Also included is a "palm card" (see figure 1) which clearly outlines nine steps for safe injection. All items are sealed in a plastic bag and labeled "use once." Injectors reported that they were much more likely to use injection equipment only once after they were educated about the risk of contracting HCV.

## PREVENTING BLOOD-BORNE INFECTIONS IN IDUS

Despite the interventions already mentioned, it is important to educate IDUs in safer injection techniques since sterile syringes may not always be available and other steps in the injection process pose a risk of infection. In Principles of HIV Prevention in Drug-Using Populations, NIDA recommends the following hierarchy of HIV/AIDS risk-reduction messages, beginning with the most effective behavioral changes that drug users can make.

- Stop using and injecting drugs.
- Enter and complete drug treatment, including relapse prevention.



figure 1 One Hit Kit Palm Card

- Never re-use or "share" syringes, water, or drug preparation equipment.
- Use only sterile syringes obtained from a reliable source (e.g., a pharmacy or a syringe access program).
- Always use a new, sterile syringe to prepare and inject drugs.
- If possible, use sterile water to prepare drugs; otherwise use clean water from a reliable source (e.g., fresh tap water).
- Always use a new or disinfected container ("cooker") and a new filter ("cotton") to prepare drugs.
- Clean the injection site with a new alcohol swab before injecting drugs.
- Safely dispose of syringes after one use.

These are very general rules for safer injection and they do not address the many issues and situations that can occur. For example, they do not address the sharing of drugs. Drug users share drugs primarily for financial reasons, not as part of a drug using "ritual," as some believe. If the drug solution is prepared and then divided, transmission can occur if any of the elements (drug preparation equipment, water, syringe) are infected. Drug users should be encouraged to divide the drug before it is prepared.

In addition, the above messages do not address what should be done in the event that a sterile syringe is not available. For years, IDUs have been encouraged to use bleach to clean their syringes and works. Using bleach only reduces the risk of transmission--it does not eliminate it. Bleach disinfection should be considered as a method to reduce the risk of HIV infection when re-using or sharing syringes (and other injection equipment) when no other safer options are available. It must be noted that while bleach can reduce the risk of HIV transmission. there has not been sufficient research to date to prove the efficacy of bleach in killing HBV and HCV. Because of these ambiguities, many prevention programs no longer advocate the use of bleach. They argue that there are only so many messages that an IDU can absorb in an outreach session. While this is clearly a reality, if possible, IDUs who must use used syringes should be encouraged to clean their syringe and works with bleach since it is known to be

effective in killing HIV and the evidence is inconclusive on HCV.

There are many resources that go into much greater detail on safer injection techniques. The Harm Reduction Coalition is a good source of these materials at <a href="http://www.harmreduction.org">http://www.harmreduction.org</a>.

While there is overlap between HIV and hepatitis prevention messages, it is also important to acknowledge the differences. HCV is far more infectious than HIV and the common prevention messages used in HIV prevention (don't share syringes) are insufficient for preventing the spread of HCV. The message to prevent all blood-borne infections must emphasize that any contact with blood-on paraphernalia, surfaces, and through sharing drugs--is risky. No longer can the message be limited to "A sterile syringe every time." It must encompass the entire process of shooting up, including the sharing of drugs.

## SERVICES FOR HBV- AND HCV-INFECTED IDUS

Many service providers have been reluctant to initiate hepatitis C counseling and testing services because they believe there is little that can be offered to those that test positive. If a person does not have health insurance, treatment may seem out of reach. However, as with any disease, there are a range of activities that can be implemented to prevent and control hepatitis.

Providers that have incorporated hepatitis-related services report that while it is a challenge to link clients to clinical care when it is indicated, it is possible, through compassionate care programs, city and county insurance programs, or other sources of care. Providers also report that hepatitis-related services act as a real "draw" for drug users. Offering HCV screening and HAV and HBV vaccines can bring drug users into the care system. Once there, providers can focus on other needs such as linking the drug user to drug treatment or other social services.

#### **Primary Prevention Education**

As discussed earlier in the document, IDUs need to be educated about HBV and HCV, taught how to reduce

their risk and protect others through the adoption of safer behaviors, and provided information on what they should do if they think they are infected.

#### Screening

The Recommendations for Prevention and Control of Hepatitis C Virus (HCV) Infection and HCV-Related Chronic Disease, (http://www.cdc.gov/mmwr/preview/mmwrhtml/00055154.htm) developed by the CDC, specify that testing should be routinely offered to people at-risk of infection with HCV.

To identify persons who should be counseled and tested for HBV and HCV, providers and counselors should routinely question individuals about risk factors, including a history of or current injection drug use. However, IDUs are often not seen in primary care or other traditional health care settings. Targeted outreach in other settings, such as correctional institutions, drug treatment programs, programs for high-risk youth, HIV counseling and testing sites, and STD clinics, may be particularly effective in reaching this populations. In addition, some HIV and STD programs offering HCV counseling and testing have found that some clients may be reluctant to report injection drug use, but less hesitant to admit to sex with an IDU. This risk question may be a good proxy for injection drug use in some circumstances.

Other groups recommended for HCV testing include, persons who received blood-clotting factors produced prior to 1987; persons who received blood transfusions or organ transplants prior to 1992; persons who have signs or symptoms of liver disease (e.g., abnormal liver enzyme tests); persons who were notified that they received blood from a donor who later tested positive for hepatitis C; children born to HCV-positive women; and health-care, emergency medical, and public safety workers after needle sticks, sharps, or mucosal exposures to HCV-positive blood. In addition, anyone who wishes to know their HCV infection status should be provided the opportunity for testing. In all instances, testing should be accompanied by appropriate counseling and referral for medical follow-up.

#### **Secondary Prevention Education**

There are specific steps a person infected with HBV and HCV should take to protect their health. One of the most important of these is to abstain from alcohol since consumption of alcohol can speed the onset of liver disease. In addition, if appropriate, infected individuals should be immunized against HAV and HBV (see below).

#### Vaccination

IDUs should be immunized against HAV and HBV infections, unless they have already been infected. Since HAV infection can be very severe in those who already have chronic liver disease from HBV or HCV infection, anyone who is infected with either HBV or HCV should be offered an HAV vaccine. The HAV vaccine is given in 2 doses, 6 months apart. The HBV vaccine is usually given in 3 doses over a 6-month period. In addition, a combined hepatitis A and hepatitis B vaccine (Twinrix) is available. This vaccine follows the same dosage schedule as the hepatitis B vaccine.

Because they are not available in a single dose, administering the vaccines to IDUs can be a challenge. After the first dose, people are required to return for the additional doses. Given the chaotic lives led by some drug users, this does not always happen. Some providers attempt to follow up with people after their first dose, through reminder cards or other methods, but these efforts are only moderately successful. Organizations working on HIV, IDU, and substance abuse issues are becoming increasingly aware of the need to provide vaccinations to those at risk. However, limited staffing, expertise, and funding for vaccines can present a barrier to adding this service to their existing efforts.

#### Treatment

Two drugs, alpha interferon (or an improved form of interferon, called pegylated interferon) and ribavirin, have been approved by the Food and Drug Administration (FDA) for the treatment of chronic hepatitis C. Interferon is either given alone or in combination with ribavirin for a 12-month period to patients who are at greatest risk of developing serious liver disease. The treatment is expensive, only moderately effective, and not appropriate for everyone infected. In addition, there can be significant side effects.

While no longer the case, earlier treatment guidelines recommended that treatment not be provided to drug users unless they had abstained from drug use for at least 6 months. The current guidelines suggest that decision to treat be made on a case by case basis. Even if antiretroviral treatment is not indicated, there are a number of steps HCV-infected IDUs should be encouraged to take to protect their health. One of the most important steps is to avoid consumption of alcohol because alcohol can accelerate the progression of liver disease.

Three drugs are also available for treating chronic hepatitis B: adefovir dipivoxil, alpha interferon, and lamivudine. Adefovir dipivoxil slows the progression of chronic hepatitis B by interfering with viral replication and causing DNA chain termination after its incorporation into viral DNA. It has been shown to be effective in treating patients with HBV that is resistant to lamivudine. Alpha interferon stimulates the immune system to fight infection. It is expensive, must be administered by injection, and has multiple side effects. Lamivudine has few, if any, side effects. Stopping lamivudine can result in relapse but continuing lamivudine indefinitely often leads to antiviral resistance.

#### INTEGRATING HCV SERVICES

Since IDUs are an extremely hard-to-reach population, any contact they have with a service provider should be used to link them with additional services. For example, drug treatment programs can link their clients to HIV and hepatitis counseling and testing. HIV outreach efforts focusing on harm reduction can also provide information and referral on drug treatment.

Many providers do not have the resources to address viral hepatitis through education, screening, vaccination and treatment. Barriers include:

- Inadequate infrastructure to incorporate additional services;
- Lack of resources and expertise to conduct training for staff; and
- · Lack of funding to increase capacity.

In addition, on the front lines, staff may be reluctant to take on more responsibilities or feel that they are not qualified to take on these responsibilities unless adequate support and training is provided. Staff may also be resistant to incorporating hepatitis services because they feel limited in their ability to address client needs due to the lack of referral options.

However, successful approaches of integration exist. The following profiles provide examples of how three health departments have integrated viral hepatitis into their existing services.

#### Multnomah County, Oregon

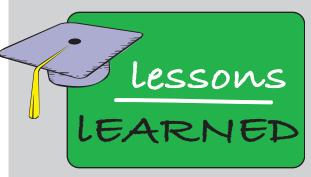
Training Staff to Integrate HCV Prevention into Existing HIV Prevention Programs for IDUs In Multnomah County, Oregon, injection drug use is pervasive and an undeniable risk factor for infection with HIV, HBV and HCV. While the HIV infection rate has remained relatively low (<5%), there is a much higher rate of HCV infection among IDUs in the Portland metro area. As a direct result of community advocacy, the Multnomah County Health Department (MCHD) began integrating hepatitis C prevention and support services into STD, counseling and testing, and HIV outreach programs in the fall of 1999.

In 2000, the MCHD formally developed the Viral Hepatitis Integration Program (VHIP). Since its inception, VHIP has provided ongoing and extensive capacity building training to HIV counseling, testing, and referral staff; STD clinicians; syringe exchange workers; HIV outreach workers; and county alcohol and drug evaluation specialists. The training is designed to prevent further HCV transmission and promote the testing of persons at highest risk for HCV in the community.

Incorporating HCV prevention into existing outreach has been a challenge, according to Alison Goldstein, a Hepatitis C Social Worker with MCHD. Goldstein notes, "The shift from an HIV risk-reduction approach to a broader, multi-infectious disease approach has required extensive support, training, and integration of previously separate disease prevention services."

Infectious disease prevention requires staff to focus on risks related to syringe sharing, drug preparation and distribution, the intricacies of sex and drugs, and the motivations behind behavioral risk activities. This communication exchange requires time, technical skill, and coordination among programs. MCHD recognized

the need for more structured service integration and staff skill building to move clients along the behavior change continuum.



- With appropriate training, HIV/STD outreach workers and counselors can adapt their prevention messages to individual clients, based on their particular risks.
- Integrating hepatitis information requires staff to focus on different messages related to syringe sharing, drug preparation and distribution, and motivations behind behavioral risks. Incorporating these messages requires time, technical skill and coordination across programs.
- Without a coordinated care system for persons diagnosed with HCV infection, job stress can increase for those responsible for providing HCV test results to clients.
- Hiring and maintaining staff with a history of drug use can be a challenge. Staff in recovery may need more coaching about boundary setting and clientcentered counseling.

Over the years, MCHD has identified the following issues that impact efforts to reach IDUs.

- There are social, legal, and practical barriers to reducing risk for diseases, such as HIV, STD's and hepatitis C.
- The benefits of drug use (numbing, reducing social inhibition, better sex) often outweigh the consequences (missing too much work, fighting with partner, having unprotected sex) for clients.
- A client's previous experience with change, readiness to reduce risk, and perceived/real barriers will either facilitate or hinder the change process.
- The client has to feel the change is important and have a sense of confidence that they can alter their behavior for risk reduction to occur.
- Measurable, meaningful risk-reduction planning must be mutually agreed upon and initiated by the client.

The above issues, as well as the increased volume of HCV-positive results, created a clear need for more structured program and service integration to assist clients with risk reduction activities. For MCHD staff, giving positive test results has become common, which has increased job stress and necessitated coordinated care systems for persons diagnosed with hepatitis C. Unlike with HIV, many MCHD staff reported feeling frustrated about giving people a positive test result for hepatitis C because of the existing service system's limited opportunities for follow up and referral. To address

this, services had to expand and be integrated to meet client needs. Presently, syringe exchange services, HIV and hepatitis C counseling and testing services, hepatitis A and B vaccination and STD treatments are all available at the centralized county STD program.

Behavioral risk activities such as trading sex for money or drugs, engaging in unprotected sex with multiple partners, sharing injection drug paraphernalia, having sex while intoxicated, and others can increase transmission of many STDs, hepatitis, and HIV. MCHD recognizes the interplay between sexual activity and drug use and referrals for testing, treatment, and support can be addressed most efficiently within this comprehensive care continuum. Nevertheless, referrals to medical care, mental health services, drug treatment, and other support services remain inadequate.

Finally, skill building efforts to move clients along the behavior change continuum resulted in challenges in hiring and maintaining staff with a history of drug use (but in recovery). The recovery history of staff clearly facilitates access to hard-to-reach communities, but it creates challenges to risk planning. Some of the "in recovery" staff struggle with the idea of harm reduction, perhaps believing that absolute abstinence from drugs and alcohol is the only way to reduce risk. Further, a staff member's personal success or failure with a drug treatment approach may be unnecessarily projected onto their clients. Often, these staff need more coaching around boundary setting and client-centered counseling.

Through training, outreach workers and counselors are learning to adapt their prevention messages to individual clients, based on their particular risks and their stage of behavior change. Service integration and staff skill building have improved MCHD's capacity to motivate clients toward behavior change and link clients to appropriate care systems. When giving test results to persons with hepatitis C, staff convey three core public health messages to clients: 1) reduce/abstain from drinking alcohol and using other drugs, 2) get vaccinated against HAV and HBV, and 3) see a health care provider routinely. These care messages are delivered to clients only after assessing their motivation for, and readiness to, change. Overall,

these fundamental program changes have improved skill and have increased staff ability to meet the ever-changing needs of IDUs.

For more information, call: Virginia Schmitz, Hepatitis C Coordinator; Alison Goldstein, Hepatitis C Social Worker; or Jessica Guernsey Camargo, HIV/Hep C Health Educator at 503-988-3030.

#### **New Mexico**

### Integrating Viral Hepatitis Services into a Statewide Harm Reduction Program

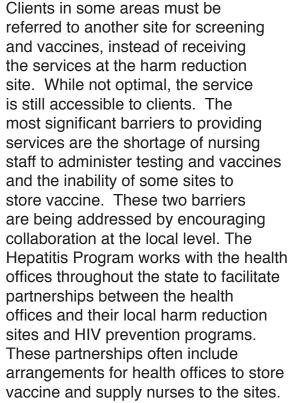
From 1994 to 1997, the New Mexico Department of Health conducted a statewide street-based seroprevalance study that showed that less than 1 percent of IDUs were infected with HIV and 82 percent had been infected with hepatitis C. These findings helped win legislative support for a statewide harm reduction program, including syringe exchange, which was initiated in 1998. Advocates for harm reduction argued that the state should take steps to protect IDUs while the prevalence of HIV was still low, in order to prevent the explosion of new cases of HIV in IDUs that had been seen in other states. The program now has an annual budget of \$700,000 and 23 sites throughout the state.

New Mexico's rates of injection drug use are higher than the national average and the state has the highest overdose rate in the country. The New Mexico Harm Reduction Program offers IDUs a wide range of services. Depending on the area served, sites are either fixed or mobile (using a van or RV). The sites provide sterile syringes, sterile packets of water, cookers, dental cotton and information on safe injection. HIV testing is available and referrals are made to HIV treatment and drug treatment. Overdose prevention information and training, as well as Narcan, are also available.

The New Mexico Department of Health has built on its harm reduction program to incorporate viral hepatitis services for this highly at-risk population. With a relatively small population, 1.8 million people, and a centralized department of health, New Mexico is well positioned to address many challenges through collaboration. Because it is not a large, centralized organization, many linkages can be informally established between staff of different programs to implement collaborative initiatives.

Since 2000, the harm reduction sites have been offering a range of state-funded services to address viral hepatitis. Hepatitis B and C screening and hepatitis A and B vaccines

are available at no cost to harm reduction program clients, often onsite. All harm reduction staff have received cross-training in viral hepatitis so that they can serve as resources to clients.



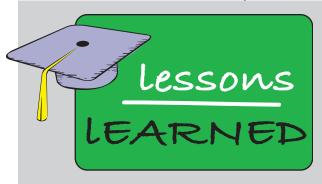
offices throughout the state to facilitate partnerships between the health offices and their local harm reduction sites and HIV prevention programs.

These partnerships often include arrangements for health offices to store vaccine and supply nurses to the sites.

One of the ways the Hepatitis Program addresses the challenge of staffing is by hiring contract nurses. Currently, there are four contract nurses, one serving each of the state's health districts. Their contracts cover a set number of hours and their only responsibilities are to provide vaccine and testing services in nontraditional settings. Within their districts, nurses are responsible for providing coverage at harm reduction sites and HIV prevention sites each week. These sites include a variety of outreach settings, including detention centers. One

Another challenge is getting clients to return for subsequent vaccine doses. Both the HAV and HBV vaccine require

nurse even visits an adult bookstore on a regular basis.



- In smaller states, integration across state programs may be easier because there is less bureaucracy and efforts may be initiated on an informal basis.
- Because each community is unique, challenges can vary at the local level, necessitating various collaborative approaches.
- Integration of services may result in compromises, given limited resources. Even if a service cannot be provided onsite, it is possible that through integration it can be provided through referral.
- Staffing shortages can be addressed in various ways-New Mexico hired part-time contract nurses.
- Hepatitis programs can offer a variety of services to HCV-infected individuals including risk reduction counseling, education on preventing disease progression, HAV and HBV immunizations, and support groups for those both in and out of treatment.

multiple doses over a period of months. While the Hepatitis Program believes it is fairly successful in this area, the program is still looking for ways to evaluate the return rate. One of the benefits of providing these services at the harm reduction sites is that the clients return to the sites for other services, especially to exchange syringes. This provides ongoing access to clients. The Hepatitis Program is experimenting with sending email reminders to clients. Many of the clients, even the homeless ones, have email--they can access it in public libraries.

The Hepatitis Program also conducts educational activities. Currently a viral hepatitis social marketing campaign, funded by the CDC, is underway. It encourages IDUs to get tested for hepatitis C and get vaccinated against HAV and HBV. The campaign also stresses the importance of avoiding alcohol for people who are infected with hepatitis C, since the program's initial focus groups indicated that many IDUs are not aware of the role of alcohol. Another message that is emphasized is the importance of not sharing works. The focus groups also found that while many IDUs know not to share syringes, they are not aware that viruses can also be spread through contaminated works.

While beyond the scope of their work, that lack of treatment options for people with hepatitis C serves as an ongoing struggle for the program and harm reduction program staff. With few exceptions, unless clients have health insurance or live in the county served by the University of New Mexico Hospital, they do not have access to treatment. While state resources are not available to provide treatment services, the Hepatitis Program is exploring ways to address some of the needs of HCV-infected clients. The program is establishing support groups for people who are infected with hepatitis but not in care (support groups are also available for people who are in care). Facilitators undergo training so that they can serve as resources and to ensure that the information provided is correct and consistent. Participation in a support group can lead to the adoption and/or maintenance of safer behaviors and also encourage participants to take steps, such as abstaining from alcohol, which will protect their health.

For more information, call: Reena Szczepanski, Hepatitis Program Manager New Mexico Department of Health, 505-827-2507.

#### Rhode Island

### Taking Advantage of Opportunities to Enhance and Expand Services

Rhode Island has relied heavily on integration at various levels to provide viral hepatitis services to IDUs. With the extremely limited resources available for hepatitis services, integration across state agencies and at the local level has been an approach adopted by many states. Through integration, the expertise, resources and ties to the target population of multiple programs can be tapped to meet the needs of the clients. In addition to collaborating at various levels, Rhode Island actively sought out resources that provided opportunities to expand and enhance services.

It is estimated that 18,000 individuals are infected with HCV in Rhode Island. Newly unduplicated laboratory reports of HCV infection in the state range from 659 identified in 1997 to over 2,600 identified in 2002. Rhode Island is in the midst of a heroin epidemic, with the number of opioid-dependent people growing and the age of onset decreasing. Currently, facilities that treat opioid dependence and those at highest risk serve 4,000 daily. It is estimated that 90 to 95 percent of the IDUs in the state are infected with HCV.

The Rhode Island Department of Health's (DOH) response to this challenge began in 1996 with a resource inventory and a prioritization exercise. The activities identified as priorities included: provider education; public education; staff development and training; expanded surveillance/epidemiologic investigations; development of a treatment infrastructure of providers willing and able to treat HCV-infected individuals; and needs assessment activities.

As a first step, DOH sought to determine how HCV-infected individuals were accessing care. In order to carry out more surveillance activities, DOH sought additional funding and, in 1997, DOH was awarded a seed grant from a pharmaceutical company. A part-time nurse was hired to conduct an assessment of the needs of HCV-infected clients in relation to access to treatment.

DOH also sought additional resources to support integration efforts. Since the 1980s, DOH has worked with the Department of Mental Health, Retardation, and

Hospitals (MHRH) in the areas of HIV, substance abuse



- Assess the availability of existing services (service inventory) and prioritize identified needs.
- Educate policymakers on the issues relating to viral hepatitis.
- Seek resources from the private sector and Federal agencies.
- Integration should not be limited to the provision of services but should include planning activities.
- Develop an advisory group of major stakeholders.

and mental health. When the two agencies began to look at ways that they could collaborate around hepatitis, they tapped into technical assistance and capacity building support from the Substance Abuse and Mental Health Services Administration's (SAMHSA). Center for Substance Abuse Treatment (CSAT). With the support from CSAT, consultants were engaged that assisted in the process of creating an interagency strategic plan to address HCV in drug users. Paul Loberti, Rhode Island AIDS Director, emphasizes the importance of the technical assistance in moving forward integration efforts. He encourages other states to take advantage of this resource.

What has evolved, as a result of integration, is a multi-layered approach to hepatitis.

At the intervention level, IDUs receive prevention services from the ENCORE (education, needle exchange, counseling, outreach and referral) program, which is administered by DOH's Office of HIV and AIDS. This statefunded syringe exchange program provides education and risk reduction services to IDUs and refers clients to hepatitis screening and immunization services.

Both DOH and MHRH participate in the HIV community planning group (CPG) and the CPG has a task force addressing substance use disorders. The CPG is instrumental in carrying out assessments that explore the variables related to this population, issuing policy statements, and advocating for more resources. In addition, in 2003, DOH established the Viral Hepatitis Advisory Group, made up of health care providers, community advocates, health insurance representatives and other hepatitis stakeholders. The purpose of the group is to assess the needs and gaps of viral hepatitis prevention and treatment services and assist in formulating a long-term strategic public health response to viral hepatitis.

DOH is also planning a Viral Hepatitis Summit for the fall of 2003 in cooperation with the states of Connecticut and Massachusetts and the Hepatitis International Foundation.

In terms of viral hepatitis-specific services, DOH has hired a HCV coordinator/program manager and a care coordinator. The care coordinator is limited to working with specific populations that include HCV-infected Department of Corrections inmates and clients of the state's methadone treatment program and syringe exchange program. Linking people to care can be extremely difficult since most do not have health insurance. Screening and vaccinations (for HAV and HBV) are available from various service providers. DOH and MHRH staff and the staff of both the agencies' vendors have received cross-training in viral hepatitis so consistent information is available to IDUs from various access points.

For more information, contact: Paul Loberti, AIDS Director, Rhode Island Department of Health, PaulL@doh.state.ri.us.



#### A Comprehensive Approach: Preventing Blood-Borne Infections Among IDUs

A technical assistance document developed by CDC describing eight complementary strategies that, when used together, can prevent blood-borne infections among IDUs. Available at http://www.cdc.gov/idu/pubs/ca/forword.htm

#### CSAT/CDC/HRSA Cross-Training Initiative

A CSAT, CDC and HRSA training and technical assistance initiative available to state and local public health programs on cross-training and collaboration across multiple programs. Information is available at http://www.treatment.org/Topics/infectious.htm.

#### CSAT Treatment Improvement Protocols (TIPs)

Best practice guidelines for the treatment of substance abuse developed by CSAT. Relevant TIPs include Tip 37: Substance Abuse Treatment for Persons with HIV/AIDS, among others. Up to five free hard copies of TIPs can be ordered from the National Clearinghouse for Drug and Alcohol Information (NCADI) by accessing its electronic catalog at http://www.health.org/about/Questions.htm or by calling 1-800-729-6686. A brief description of each TIP and its NCADI order number is available at http://www.treatment.org/Externals/tips.html. Many TIPS are available online for download.

#### The NIDA Community-Based Outreach Model: A Manual to Reduce the Risks of HIV and other Blood-Borne Infections in Drug Users

Provides principles for the prevention of blood-borne infections for out of treatment drug users. Available at http://drugabuse.gov/CBOM/index.htm.

#### Principles of HIV Prevention in Drug-Using Populations

This guide, developed by the National Institute on Drug Abuse (NIDA), summarizes the basic overarching principles that characterize effective HIV/AIDS prevention in drug-using populations. The guide is available at: <a href="http://drugabuse.gov/POHP/">http://drugabuse.gov/POHP/</a>

#### Principles of Drug Addiction Treatment

This guide, developed by the NIDA, summarizes the basic principles of drug treatment and describes different treatment options. Available at http://drugabuse.gov/PODAT/PODATindex.htm.

NASTAD's Joint Statement on Safe Community Needle Disposal Joint statement issued by the American Diabetes Association (ADA), American Association of Diabetes Educators (AADE), American

Medical Association (AMA), American Pharmaceutical Association (APhA), Association of State and Territorial Health Officials (ASTHO) and NASTAD on the importance of developing safe and convenient community disposal options for used needles and syringes. Available online at <a href="http://www.nastad.org/pro\_viral\_hepatitis.asp?menu=pro">http://www.nastad.org/pro\_viral\_hepatitis.asp?menu=pro</a>.

### NASTAD's Joint Statement on HIV Prevention and Access to Sterile Syringes

Joint statement issued by the American Medical Association (AMA), American Pharmaceutical Association (APhA), Association of State and Territorial Health Officials (ASTHO), NASTAD and the National Association of Boards of Pharmacy (NABP) recommending the removal or modification of legal barriers to increase the availability of sterile syringes through pharmacies. Available online at: http://www.nastad.org/pro\_viral\_hepatitis.asp?menu=pro.

#### Addiction Technology Transfer Centers

http://www.nattc.org

The ATTC Network is dedicated to identifying and advancing opportunities for improving addiction treatment. The Network is funded by the Substance Abuse and Mental Health Services Administration (SAMHSA).

#### American Liver Foundation

#### http://www.liverfoundation.org

Contains numerous resources on hepatitis, including a page dedicated to hepatitis-related information for drug users.

### Centers for Disease Control and Prevention, Division of Viral Hepatitis

#### http://www.cdc.gov/hepatitis

Offers free brochures; frequently asked questions on HIV-HCV co-infection; slide sets on HAV, HBV and HCV; CDC publications and more.

### Centers for Disease Control and Prevention, HIV Prevention among Injection Drug Users

#### http://www.cdc.gov/idu

A collection of fact sheets and other resources addressing HIV prevention, viral hepatitis, drug treatment, criminal justices and other topics.

#### Harm Reduction Coalition

#### http://www.harmreduction.org

Includes a broad range of resources on harm reduction and syringe exchange. Also has a brochure exchange where brochures from various programs can be downloaded.

#### HIVandHepatitis.Com

#### http://www.HIVandHepatitis.Com

Includes a wide range of treatment information for HIV and hepatitis.

#### National Alliance of State and Territorial AIDS Directors, Viral Hepatitis Program

http://www.nastad.org/pro\_viral\_hepatitis.asp?menu=pro.

The program provides guidance and information on developing appropriate staff expertise on viral hepatitis and incorporating viral hepatitis issues into existing program infrastructures. Materials are intended for use by state, territorial, county, and local HIV/AIDS programs, larger non-governmental HIV/AIDS service providers, and other public health agencies.

#### National Institute on Drug Abuse

http://www.nida.nih.gov

Information related to addiction and treatment

#### North American Syringe Exchange Network

http://www.nasen.org

Resources on syringe exchange and harm reduction as well as information on their seed grant program for syringe exchange programs.

#### SAMHSA Center for Substance Abuse Treatment

http://www.samhsa.gov/centers/csat2002/csat\_frame.html Information on prevention and treatment of substance abuse.

information on prevention and treatment of substance abuse

### *Temple University, Law, Policy and Public Health* http://www.temple.edu/lawschool/phrhcs/phrhsc.htm

Contains comprehensive and current detailed legal analysis on the legality of prescribing, selling, possessing and disposing of syringes used in illegal drug injection.

# 6

**Tapping Into the** 

## Viral Hepatitis Community

# Tapping Into the Viral Hepatitis Community

n the last few years, the media have focused on newly emerging health threats—SARS, West Nile virus, monkeypox, drug-resistant bacteria, and others. In addition, other high-profile, health-related issues such as bioter-rorism and prescription coverage for the elderly have been the focus of policy-makers at the national level. In the course of health-related discussions, whether they are at the local, state, or national level, viral hepatitis rarely receives a mention. However, viral hepatitis, which for the purpose of this document refers to hepatitis A virus (HAV), hepatitis B virus (HBV), and hepatitis C virus (HCV) infections, is a significant public health challenge for various reasons, some of which are listed below.

- Both hepatitis B and C viruses are highly infectious, blood-borne viruses (much more infectious than HIV).
- Infection with one or more of the three types of viral hepatitis can have serious health consequences. Infection with chronic hepatitis B or chronic hepatitis C can lead to cirrhosis, liver cancer, and death.
- All three types of viral hepatitis can be prevented through behavior change, and hepatitis A and B are also vaccine-preventable.
- Many people who are infected may have never heard of viral hepatitis. Some people infected with hepatitis B and/or hepatitis C were infected 10 to 20 years ago and no longer engage in the behaviors that put them at risk. Because they are not currently at

<sup>&</sup>lt;sup>1</sup>Hepatitis A, B, and C are the most common types of viral hepatitis in the U.S.

risk of infection, they may not respond to awareness efforts and are probably not accessing HIV or STD prevention services. Specific outreach strategies are required for these individuals.

 Viral hepatitis affects multiple, diverse populations, necessitating various prevention strategies.

Hepatitis A, B, and C share many similarities with HIV and other STDs, as they affect many of the same populations. They all can pose a serious health threat, either separately or in interaction with each other.

Hepatitis A is caused by an infection with HAV. HAV is transmitted primarily by oral contact with the feces of an infected person. This occurs most often by sexual or household contact with an infected person. Hepatitis A can also occur through ingestion of HAV-contaminated food or water. Men who have sex with men (MSM) and injecting and noninjecting drug users are at increased risk for contracting HAV infection. Hepatitis A vaccination is recommended for these high-risk groups. Increased rates of HAV infection are common in some areas of the world, and vaccination is recommended for travelers to those areas.

Hepatitis B is a blood-borne disease caused by infection with HBV. HBV is transmitted primarily through sexual contact with an infected person. Populations at risk of infection include MSM, persons with multiple sex partners, persons with an STD infection, injection drug users (IDUs), household contacts of persons chronically infected with HBV, and infants born to infected mothers. As with hepatitis A, in certain areas of the world, hepatitis B is endemic in the population, and infants or immigrants from these parts of the world may be at higher risk of infection. The risk of infection among health care workers has substantially declined, due to large-scale vaccination programs. Like hepatitis A, hepatitis B is vaccine-preventable, and vaccination is recommended for all persons at risk.

**Hepatitis C** is the most prevalent type of chronic viral hepatitis in the United States; an estimated 3.9 million

An estimated 3.9 million Americans have been infected with HCV, and 2.7 million Americans are chronically infected.

Table 1. Disease Burden From Hepatitis A, B, and C in the United States

	Hepatitis A		Hepatitis B		Hepatitis C	
	2001	2000	2001	2000	2001	2000
Number of Acute Clinical Cases Reported	10,616	13,397	7,844	8,036	no data	
Estimated Number of Acute Clinical Cases	45,000	57,000	22,000	22,000	4,000	5,700
Estimated Number of New Infections	93,000	143,000	78,000	81,000	25,000	35,000
Number of Persons With Chronic Infection	no chronic infection		1.25 million		2.7 million	
Estimated Annual Number of Chronic Liver Disease Deaths	no chronic infection		5,000		8,000-10,000	
Percent Ever Infected	31.3%		4.9%		1.8%	

Source: Division of Viral Hepatitis, National Center for Infectious Diseases, Centers for Disease Control and Prevention (http://www.cdc.gov/ncidod/diseases/hepatitis/resource/dz\_burden02.htm)

Americans have been infected with HCV, and 2.7 million Americans are chronically infected. HCV is transmitted through blood-to-blood contact with an infected person, and injection drug use is currently the primary risk factor for transmission. In the past, persons with specific medical conditions have been at high risk of infection. These include individuals who received a blood transfusion or organ transplant before July 1992, persons who were ever on longterm hemodialysis, and persons who received clotting factor concentrates before 1987. Other persons who are currently at risk of infection include health care and public safety workers who are exposed to HCVinfected blood, and children born to HCV-infected mothers. Studies have found that African Americans, Latinos, and incarcerated individuals are disproportionately affected by HCV.

Despite the magnitude of viral hepatitis in the United States, the public health response to this epidemic

remains insufficient, in large part due to the limited federal resources available for hepatitis services

#### **Role of Hepatitis C Coordinators**

CDC's Division of Viral Hepatitis (DVH) funds a national Hepatitis C Coordinator Program. In each state, the Hepatitis C Coordinator serves as a liaison with other public health programs, including HIV/STD, substance abuse, immunization, and corrections. The goal of the coordinator position is to help integrate viral hepatitis services (hepatitis C counseling and testing, hepatitis A and B vaccines) into existing prevention programs.

Hepatitis C Coordinators must play various roles. Perhaps most importantly, they must provide leadership and increase the visibility of viral hepatitis as an issue of importance. They must also identify stakeholders and recruit them to the cause. Finally, they must become adept at identifying resources at the local, state, and national levels.

(e.g., prevention, screening, vaccination, referral for medical evaluation). For over 10 years. there have been recommendations to vaccinate MSM and other high-risk adults against hepatitis B, but without federal dollars to support vaccine purchase and infrastructure development, immunization rates among MSM remain low, and the virus continues to be transmitted. Similarly, the Centers for Disease Control and Prevention's (CDC) 2001 Hepatitis C Prevention Strategy outlined a comprehensive plan for the prevention and control of HCV. but without a substantial increase in resources, state and local public health programs have been unable to fully implement the recommended actions.

Several state legislatures have responded to the hepatitis C epidemic by appropriating funds, but with the current fiscal crisis in most states, many have seen the hepatitis appropriation decreased or cut. It is unlikely that in the current fiscal climate, state and local health departments will be able to tap into sufficient state funds to address needs.

The lack of resources has created something of a dilemma for service providers at the local level. Charged with creating awareness among at-risk populations, providers worry that resources will not be sufficient to meet the resulting demand for services such as screening and appropriate follow-up.

Given the lack of resources, most state and local public health programs seek to integrate viral hepatitis services within existing services, such as HIV, STD, and immunization. Through integration, hepatitis programs can capitalize on existing programmatic infrastructure and experience in reaching populations at risk. Coordinating and consolidating these activities within a health department can be a challenge. Taking the next step to involve the community in the response to hepatitis also requires considerable effort. However, given the scarcity of resources, involving community-based organizations (CBOs) and affected populations in the state and local response is one of the few options available to local health departments for expanding services in response to growing demand.

### THE ROLE OF CBOs AND AFFECTED POPULATIONS

This document focuses on the role of CBOs and affected populations in the community-level response to viral hepatitis. For various reasons, CBOs and affected populations are key components of the response to viral hepatitis at the local level.

Most significantly, given that the lack of resources is, for most communities, the greatest challenge to service delivery, integrating the efforts of CBOs and affected populations can expand service availability. Expanding existing services through integration can be less expensive than establishing new services. In addition, CBOs and affected communities can play an important advocacy role. In increasing awareness about the impact of viral hepatitis and the unmet service needs, CBOs and affected populations can be instrumental in securing the resources needed to address the epidemic.

CBOs are known for providing cost-effective services. They are experienced in doing more with less and often have tapped into nonfinancial resources within the community, such as the use of volunteers and other types of in-kind donations. They also may have ties to the local philanthropic community that can be beneficial to future endeavors. However, as CBOs integrate new activities, they may need additional

Integrating the efforts of CBOs and affected populations can expand service availability.

#### Benefits of Involving CBOs

- Tie to affected populations
- Recognized and trusted providers of services
- Culturally sensitive/competent
- Knowledgeable of community resources (funding, volunteers, other CBOs, etc.)
- Have an existing service infrastructure

#### Benefits of Involving Affected Populations

- Can provide insight on how to effectively reach affected populations
- Have first-hand knowledge of the needs of affected populations
- Can "put a face on the issue" and serve as effective advocates
- Can serve as "peer" workers in both outreach and support efforts

support in training for staff and management, handling new administrative responsibilities, and identifying resources specific to hepatitis.

Involving affected populations in the community-level response to viral hepatitis may present some challenges. For various reasons, to be discussed later, the viral hepatitis epidemic has not spawned the rise of patient advocacy organizations that has resulted with other health-related conditions (although this is changing). Also, because it may take 10 to 20 years before people who are infected with hepatitis B or C become symptomatic, people with hepatitis may not feel compelled to take on an advocacy role.

However, to ensure that services reflect the needs of the community and are sensitive to affected populations, both CBOs and affected populations should be involved in the community-level response. For example, CBOs are often better able to reach targeted populations because they are indigenous to the community, have a history of serving

local residents, and are viewed as a resource.

Health care providers have not always recognized the value of involving affected communities in the local response. However, as we have learned from the HIV epidemic, listening to those who are confronting the illness can greatly enhance awareness efforts and the delivery of health care services. Affected populations have the knowledge and experience about reaching people at risk and the service needs of those who are infected, which health care providers and public health professionals cannot match. They are the best spokespersons to express their needs and to raise awareness of the disease. In addition, some subpopulations affected by hepatitis, such as IDUs and minorities, are distrustful of mainstream service providers. Involving these populations in the community's response can help build their trust.

#### **Hep-C ALERT: CBO Grows Through Integration**



With so much that needs to be done to address hepatitis in the United States and so few organizations to do it, hepatitis-related community-based organizations can find themselves serving in a wide range of capacities. That is the story of Hep-C ALERT. Founded in South Florida in July 1997, this CBO has since carried out various successful services addressing hepatitis at the local, state, and national levels.

Hep-C ALERT started as an Internet-based organization. It expanded to provide local support groups and resources, such as newsletters, targeting people living with HCV. In 1999, the organization received its first major grant and partnered with the Florida Association of Health Maintenance Organizations (HMOs) to provide a statewide, toll-free English/Spanish hepatitis C education, counseling, and referral hotline. Soon fielding calls nationwide, 877-HELP-4-HEP continues today as one of the country's top health education and support hotlines.

Also in 1999, Hep-C ALERT embarked on a direction that would take it to a truly national level, working with the fire and rescue industry. Work began at the local level with presentations to fire and rescue personnel in South Florida. Based on the overwhelmingly positive response from both personnel and management, a fully integrated hepatitis C education and screening program was created, and a research protocol was designed. The study methods included education, informed consent, confidential hepatitis C testing, and post-test notification. The program was piloted at the Coral Gables Fire and Rescue Department in November 1999 and expanded to the Miami-Dade Fire Rescue Department in March 2000. A total of 3,362 personnel from 11 different Florida Fire and Police Departments participated in the study. In June 2000, Oregon Health Sciences University used the same protocol for a similar study commissioned by the Oregon Legislature, with Hep-C ALERT performing the field services. Hep-C ALERT has worked with the International Association of Fire Fighters to conduct a screening program at their annual conference and by fire rescue and police departments in nine other states. After September 11, 2001, the priorities of fire and rescue workers changed dramatically, and the demand for Hep-C ALERT's services declined. However, a grant was awarded in 2003 for Hep-C ALERT to educate and provide baseline hepatitis C testing for all Broward Country firefighters and paramedics over the next year.

Currently, in addition to continuing to focus on health education and testing activities in South Florida, Hep-C ALERT is conducting the following two programs.

#### • Addiction Recovery Hepatitis Intervention Project

Hep-C ALERT is collaborating with six drug treatment programs and the state health department to provide staff training, patient education, hepatitis C counseling and testing, and hepatitis A and B vaccination. In nine months of the project, over 750 patients were served, with 84 percent being tested for HCV, 82 percent receiving the first dose of the HBV vaccine, and 91 percent of those who remained in the drug treatment program completing the second dose of the HBV vaccine.

#### • Co-Infection Connection

In 2002, Hep-C ALERT became a registered HIV testing provider. Hep-C ALERT is collaborating with an HIV organization to provide integrated HIV/HCV outreach, counseling, testing, and referral services to their clients.

Collaboration with other organizations was key in all these activities. Through collaboration, Hep-C ALERT has identified a variety of facilitators and challenges, profiled on the next page.

#### **Facilitators**

#### • Reaching out to other organizations, especially those without hepatitis expertise.

Nonhepatitis service providers, such as HIV and substance abuse treatment organizations, are becoming aware of viral hepatitis because it is affecting their clients. They do not have the capacity to address the issue, but they recognize that it is necessary to do so. Hep-C ALERT made itself known in the community by networking, attending meetings, and letting people know the organization was willing to work with them.

#### • Recognizing the importance of a mentor.

Hep-C ALERT found a "mentor" who facilitated their collaboration with HIV service providers by vouching for their credibility as a provider. A mentor is key, because provider communities can be insular and distrustful of outsiders.

#### • Providing what no one else can.

By being able to provide hepatitis C health education, counseling, and testing, which are highly sought-after services, Hep-C ALERT became a highly attractive collaborative partner. They also offered several train-the-trainer programs to other agencies to encourage and increase communitywide capacity for viral hepatitis services.

#### **Challenges**

#### • Funding is an ongoing challenge.

However, funders recognize the advantages of collaboration and appear to favor funding collaborative activities.

#### • Collaboration should be truly collaborative.

For example, serving as a subcontractor, with no say in the project, is not collaboration. Collaborators need to act as equals and determine common goals, objectives, strategies, and outcomes. Partners must trust each other, and all partners must contribute to the delivery of a quality service.

#### • Sharing organizational resources is beneficial.

Any community usually has one logical provider of a service and many others who would provide that service, with varying degrees of success, if paid to do so. Hep-C ALERT has made it a point not to provide services outside of its goals as an organization and has aided other organizations in securing funds to provide these services. In one instance, Hep-C ALERT wrote a grant for another organization because the funded services would benefit Hep-C ALERT clients.

#### • Collaboration, like any relationship, is work.

At some point, an organization needs to assess what it is gaining from a collaborative arrangement. Doing so is not always an indictment of one's collaborators. With today's funding realities, organizations are often squeezed by their major funder and have little leeway to add auxiliary services. However, if an organization finds that their collaborator cannot deliver, they should not hesitate to look for another provider that is more responsive.

In the face of overwhelming demand for diverse services in an environment where funding is difficult to identify, and transitory once it has been secured, Hep-C ALERT has pulled together a core of services to meet the needs of people living with hepatitis in South Florida. As Hep-C ALERT President Andi Thomas acknowledges, however, the real need is to educate policymakers, other service providers, and the general public on the significance of hepatitis-related services, given the impact that hepatitis will have on society in the coming years.

For more information on Hep-C ALERT go to: http://www.hep-C-alert.org.

### RESPONDING TO VIRAL HEPATITIS AT THE LOCAL LEVEL

Because of the overlap between HIV and hepatitis (the diseases have similar transmission modes), many have wondered why the public health response to viral hepatitis has been less robust than with HIV. Reasons include the following:

- Many people infected with viral hepatitis are asympomatic and consequently unaware of their infection. This is particularly true of HCV infection, which has been characterized as a "hidden" or "silent" epidemic. Many people only begin to experience symptoms 10 to 20 years after infection, when complications of liver disease begin to occur.
- Hepatitis does not carry the same stigma as HIV did in the early days of the epidemic. Because there is less fear of discrimination, people living with hepatitis may not have the same impetus to bond together and advocate on their own behalf.
- Because most people with hepatitis do not get seriously ill immediately, if at all, there has not been the need to develop the wide range of support services that were required with HIV (housing, meal programs, etc.).
- Many of the populations affected by viral hepatitis, such as IDUs, MSM, immigrants, and people of color, are traditionally disenfranchised and underserved populations. They may distrust mainstream service providers and be skeptical that any advocacy efforts will result in change.
- People who were infected years ago may not feel a need to advocate. Many are now "baby boomers" with jobs that provide health coverage. Their focus may be living a "normal" life, and they may not be compelled to advocate for greater awareness and additional services. Also, some

Because there is less fear of discrimination, people living with hepatitis may not have the same impetus to bond together and advocate on their own behalf.

stigma is still attached to hepatitis. Given that they do not see any direct benefits resulting from their advocacy effort, they may not want to risk becoming involved in the issue.

Because of these reasons, in most areas, there are no existing networks of affected populations working together to advocate for and provide hepatitis-related services. This trend is changing, however. Awareness of hepatitis is growing, and as more people become aware of the risk and their serostatus, the demand for services is increasing. The services required to meet demand are diverse, and can include harm reduction services for people who continue to inject drugs, drug treatment, screening, vaccination, support groups, clinical treatment, case management, and mental health services. Given that it is unlikely that significant increases in funding and other resources will be available from the federal government, how will your community address this demand? The following section provides an overview of how to respond to viral hepatitis in your community.

#### What's Happening in Your Community?

The first step in drawing upon and integrating existing services is to be aware of them. Since every community is different, it is impossible to provide a precise process for integration. However, some general guidelines are provided here.

#### 1. Build Interest in the Issue

To build interest in viral hepatitis at the local level, you must first be able to demonstrate that it is an issue relevant to your community. Building interest is essential to:

- Lay a groundwork for advocacy efforts with policymakers at the local, state, and national level.
- Create buy-in with potential collaborative partners.

- Lay the foundation for awareness activities targeting both the general public and at-risk communities.
- Tap into other efforts addressing viral hepatitis of which you might not be aware.

#### At this point...

- Develop a list of why viral hepatitis is an important issue for your community. Topics to cover might include:
  - Epidemiologic data on viral hepatitis and surrogate markers such as drug use, STD rates, and HIV rates.
  - Current services and service providers.
  - Special concerns such as a high level of injection drug use, lack of syringe exchange programs, increasing rates of syphilis, or high incarceration rates.
- Develop a fact sheet on viral hepatitis that incorporates local data and reflects the issues identified in your list of important issues.
- 3. Develop a preliminary Action Plan for your community. Consider this a living document that will change as more stakeholders become involved in the process. The plan should be a logical progression of activities designed to engage stakeholders, educate policymakers, create awareness in the general population, reach at-risk individuals, and implement needed services.

#### **Potential Stakeholders**

#### **Consumers/Clients**

- Affected populations, including current and former drug users, MSM, incarcerated and formerly incarcerated individuals, health care providers, hemophiliacs, transfusion and blood product recipients, and people of color.
- Organizations representing affected populations, such as professional organizations for health care providers and emergency response professionals, and organizations representing specific, at-risk subpopulations (hemophiliacs, people of color).

#### **Policymakers**

- State legislators and staff
- Governors and staff
- State health directors
- Local elected officials (city and county)

#### **Service Providers**

- Drug treatment providers
- Drug prevention organizations
- AIDS service organizations
- STD service providers
- Gay/Lesbian/Bisexual/Transgender organizations
- Corrections
- Health education and outreach organizations
- Veterans Administration (VA) hospitals
- Managed care organizations
- Community health centers
- Public hospitals (or other indigent care providers)

#### Others

- Foundations with an interest in health care
- Representatives of the health insurance industry
- Pharmaceutical company representatives
- Blood bank industry
- Transplantation organization
- Liver-related organizations
- Church leaders

#### 2. Identify Stakeholders

"Stakeholders" is a catchall term for anyone or any organization that has an interest in the issue. When casting the stakeholders net, make it as wide as possible. Think long and hard about organizations with an interest in the issue.

Stakeholders are a diverse group. They present various perspectives and offer an array of skills and expertise. Consumers/affected populations can provide insight into reaching populations at risk. as well as service needs. Policymakers can be instrumental in securing more funding or can help to enact policies favorable to integrating or expanding services. Service providers, such as drug treatment providers and STD service providers, can help expand available services through integration or provide access to at-risk populations that they may be serving.

#### At this point...

- Consider having a community forum on viral hepatitis. This may be a good way to reach out to people who have been overlooked.
- 2. Ask stakeholders to identify additional stakeholders. To do this, consider conducting a survey or interviewing key informants.

### Reaching Those Affected by Hepatitis

Even with the understanding of the importance of including affected populations in your efforts, it is sometimes difficult to identify which individuals to include. One strategy for identifying potential participants is through organizations providing services to populations affected by hepatitis, such as harm reduction services and drug treatment programs. Also, numerous patient support groups have been formed across the country. The following organizations include listings of patient support groups that may help you identify one in your community.

- American Liver Foundation http://www.liverfoundation.org/db-list/ chapter/2/ascend/ChapterName/Validated
- Hepatitis B Information and Support List
   A list-serv that provides resources information
   and support to persons living with hepatitis B
   and/or their family and friends. http://
   www.geocities.com/Heartland/Estates/9350/
   hblist.html
- Hepatitis B Foundation http://www.hepb.org/02-0072.hepb
- Hepatitis C Education and Support Network
   http://www.hepcesn.org/contact2.htm
- Hepatitis C Support Project http://www.hcvadvocate.org/community/ community.asp
- Hepatitis Foundation International http://www.hepfi.org/pages/support\_start.html
- Hepatitis Magazine http://www.hepatitismag.com/supportgroups/ default.asp
- National Hepatitis C Advocacy Council
   The National Hepatitis C Advocacy Council
   also includes information on how to start a
   support group on their Web site. http://
   www.hepcnetwork.org/

Identify the skills of your stakeholders. In addition to having an interest in viral hepatitis, individual stakeholders may have ties to policymakers, experience in conducting social marketing campaigns, ties to foundations, or connections with the local media, that may be valuable in your efforts.

### 3. Promote Meaningful Community Involvement

While the end goal may be integrating hepatitis services across organizations within a community, the community can be involved in a variety of ways in the planning and delivery of hepatitis services:

- Advocacy. Educate key audiences, such as policymakers, about viral hepatitis and its impact on the community. Methods include face-toface meetings, briefings, and the development of documents such as fact sheets and white papers (also called position papers or issue briefs) that include recommendations.
- Community Education. In addition to reaching policymakers and at-risk populations, it is important to educate the general public about viral hepatitis, focusing both on the risk factors and the need to address the virus as a public health concern.
- Advisory Committee. An advisory committee provides stakeholders with a forum for expressing their

Stakeholders can provide a wealth of information in key informant interviews or as focus group participants. concerns and voicing their expertise. These committees can take on a leadership role and become champions of the issue. In addition to a free-standing advisory committee, consider integrating stakeholders into other health-related groups in the community, such as the HIV prevention community planning group (CPG) or CARE Act planning groups.

- Needs Assessment. A needs assessment is the process used to determine the current status and needs related to a specific condition or issue, for a defined population or geographic area. The process involves collecting and analyzing primary and secondary data related to a particular topic. Stakeholders, with their knowledge of viral hepatitis and the community, can play a key role in the needs assessment process. For example, stakeholders can provide a wealth of information in key informant interviews or as focus group participants.
- Strategic Plan. A strategic plan is a written document that details a problem and defines how to best address the problem within a certain timeframe. A strategic plan should address:
  - What needs to be done
  - What resources can be drawn upon
  - Who will do the work
  - How the work will be done
  - How it will be evaluated

Stakeholders can play an important role in developing and implementing a community's strategic plan.

Strategic plans can provide a clear vision that helps focus the work and avoid duplication of effort. Planning does not stop with the development of a strategic plan. Planning activities must continue after the plan is implemented to ensure that specific activities are carried out and that they have the intended impact. Consider the plan a "living" document that can be adjusted as needs change.

#### 4. "Grow" Community Involvement

Community involvement is not an organic process that grows of its own accord. It must be nurtured.

### Needs Assessment and Strategic Planning Resources

#### HRSA/HAB Needs Assessment Guide

Although tailored for CARE Act grantees, this document discusses the components of a needs assessment, the process, and how to use results. http://hab.hrsa.gov/tools/needs/

### Starting Up: First Steps Towards the Integration of Viral Hepatitis Into HIV/AIDS/STD Programs

A NASTAD publication providing information on needs assessments and strategic planning.

http://www.nastad.org/ pro\_viral\_hepatitis.asp?menu=pro

### Examples of Needs Assessments and Strategic Plans

Needs Assessment: Maine

http://www.state.me.us/dhs/boh/ddc/hepcfull.doc

Strategic Plan: California

http://www.dhs.ca.gov/ps/dcdc/pdf/

Hepatitis%20C%20Strategic%20Plan%20-

%202001.pdf

Strategic Plan: Colorado

http://www.cdphe.state.co.us/dc/hepatitis/

hep home.asp

Strategic Plan: Wisconsin

http://www.dhfs.state.wi.us/dph bcd/hepatitis/

index.htm

Many pitfalls can occur along the way. The benefits of involving CBOs and affected populations in a community's efforts to address hepatitis cannot be underestimated. However, as with any effort that involves multiple parties, care must be taken to ensure that the process and the outcomes benefit those involved. Listed below are common pitfalls that can occur in efforts to involve the community in your activities.

- Tokenism. Involving CBOs and affected populations for the sake of appearance serves no one's purpose. Unless they can contribute to the process in a valid way, participating in your activities can be a frustrating waste of time. The input of affected populations and CBOs in the process should carry the same weight as other players, including your own.
- Infighting. Rivalries among various organizations or individuals are common. Af ter all, these entities often compete for limited commu nity resources. However, infighting can derail efforts to integrate services. Con-

Failure to act on input constitutes a significant breach of trust and can eliminate the possibility of future collaboration.

sider having a facilitator at stakeholder or advisory committee meetings and designing meetings so that everyone has an opportunity to express their opinion. Such processes as conducting a needs assessment and developing a strategic plan can also help to limit infighting. A cooperative effort to identify the community's needs and develop a plan to address the needs, complete with specific tasks assigned to community players, can help avoid the likelihood of some organizations or individuals feeling that they did not receive the recognition they deserved and their fair share of the resources.

- Plies, people are involved in the issue because they have a stake in it. This stake can sometimes lead to real or perceived conflicts of interest. For example, if the advisory committee is making recommendations about resource allocation, some members of the advisory committee will likely represent organizations that will receive resources as a result of their decisions. This can appear to be a conflict of interest that may reflect on the legitimacy of the process. Consider setting up a process for disclosing conflicts of interest and making sure that all members are aware of areas where conflicts of interest could occur.
- No Follow Through on Community Input. Perhaps the most significant threat to ongoing community involvement is a failure to act on suggestions provided by CBOs and affected populations. No one likes to waste time. However, that is exactly how people who participate in the process will feel if they do not see any results from their input. Of course, circumstances beyond control can affect a community's response, such as changes in funding levels, an increase in cases, and availability of new, more expensive treatments. If so, and the community's input is not acted upon, be prepared to explain why and to involve the community in developing an alternative plan. Failure to act on input constitutes a significant breach of trust and can eliminate the possibility of future collaboration.

#### Growing a Collaboration: The Colorado Experience

Most grassroots movements grow from the efforts of one person or a small group who identify a need and work to address it. In 1995, a group of hepatitis-C-infected individuals and their families and friends in Denver, Colorado, joined together to serve as a resource for people affected by the disease. They formed Hep C Connection and initially focused on developing a plan for telephone information and referral and a support group model to be implemented in Colorado.



While serving as a resource for infected individuals and the general public, the organization also worked to educate state legislators about the problem and the lack of resources to address it. They networked with various stakeholders in the

community, including the University of Colorado Health Sciences Center, Departments of Hepatology and Microbiology; the Veterans Affairs Medical Center in Denver; the Colorado Department of Public Health and Environment; and other health-related CBOs. Along with pushing for the passage of a law mandating Workers' Compensation benefits to public safety workers contracting hepatitis C on the job, Hep C Connection played a key role in securing state funding for hepatitis C services from the General Assembly in 1999. The funding went to the Colorado Department of Public Health and Environment, which in turn released an RFP soliciting proposals from service providers. Hep C Connection was awarded the funds.

With the funding, which is now \$127,000 a year, Hep C Connection provides a range of services including public information and referral (through a hotline), train-the-trainer activities, and outreach to high-risk individuals. Hep C Connection subcontracts with other CBOs to carry out some of the services.

According to Mauricio Palacio, the Hepatitis C Coordinator for the Department of Public Health and Environment, working with CBOs has been beneficial for several reasons:

- 1. Through their advocacy efforts, Hep C Connection was instrumental in securing state funds to carry out activities.
- 2. Hep C Connection had networked with many other stakeholders in the community and could draw on these contacts. They also had an existing infrastructure that could be expanded to provide more hepatitis C services, which the Health Department did not have.
- 3. The agency was well-positioned to provide sensitive and personalized services to clients, since many of the people involved with Hep C Connection are also infected.

Hep C Connection did require some capacity-building assistance from the health department. Since the founders of the organization had, for the most part, been infected as a result of blood transfusions, much of their outreach efforts were focused on this population. They did not have experience in working with other high-risk populations, especially IDUs. Hep C Connection hired a social worker who networked extensively with organizations serving other high-risk populations, especially HIV and STD agencies. Also, before the grant from the health department, Hep C Connection had received funding primarily from foundations and private donations. The agency did not have experience in meeting the reporting requirements associated with public funding. The health department worked with the organization in this area.

"Working with the health department provided access to a broader range of talents," says Kathy Jensen, Director of Information and Community Outreach for Hep C Connection. "The health department has expertise in evaluation and developing outcomes and measures, which helps us to document our accomplishments. This allows us to show our other funders and legislators our successes."

Jensen cites several factors that have facilitated working with the health department. Hep C Connection worked very hard to develop the trust of the health department from the very beginning. Since the organization was carrying out education and outreach activities, it was essential that the information provided be accurate and credible. The agency worked with the health department to identify the most appropriate information to provide. Also, the agency regularly communicates with the health department through required reports and other methods. Finally, the agency coordinates "Team Hep C," a network of service

providers addressing the issues, and holds regular monthly meetings, which keep the health department and the broader community informed.

"The networking involved in these efforts can be time consuming," admits Jensen. "You have to work with more people and make sure that everyone is in the loop. There will also be times when you have to give up some control."

Palacio also identified actions on the part of Hep C Connection that increased the confidence of the health department. "They engaged in a strategic planning process that really made the priorities and goals of the organization clear," he says. "We knew that they were going in a direction that was consistent with our goals."

The collaboration has lead to benefits beyond the scope of the health department's and Hep C Connection's activities. An AIDS Education and Training Centers (AETC) Center of Excellence focusing on hepatitis and HIV co-infection was recently funded in the state. The health department and Hep C Connection serve on the advisory committee. The Center for Excellence will focus on providing training to infectious disease specialists on how to treat hepatitis so that co-infected individuals can receive better, more coordinated care.

While both the health department and Hep C Connection place a great deal of value on the collaboration, and the benefits of the services to affected individuals are evident. Palacio emphasizes that the funds the health department provide to the organization are a critical part of the relationship. The funding that Hep C Connection's advocacy efforts secured from the General Assembly serves as the glue in the relationship.

"We have a really good relationship, but money plays a key role. If the state money disappeared, it would impact the relationship and the services that are provided," says Palacio.

The critical role funding plays was recently reinforced when Hep C Connection, as with many hepatitis service providers around the country, lost some of their private funding. As a result, the organization had to reduce staff and hours of operation.

"The bottom line is that collaboration can only go so far," says Palacio. "If we lose the state funding, we won't be able to provide the services. That is why the advocacy work that these CBOs do is so critical."

#### **Lessons Learned**

- Build a large network of stakeholders and work with them on an ongoing basis.
- Realize that advocacy efforts focusing on policymakers can result in availability of additional resources.
- Include partners in the program design process. Successful collaborations begin at the planning stage.
- Be open to suggestions and advice from collaborative partners.
- Recognize that your collaborative partners may have additional priorities outside the scope of your collaboration and, if possible, support these priorities.
- Leverage partners' expertise that your organization may not have.
- Be willing to give up some control when participating in collaborative projects.
- Be a partner who instills confidence. Strive to carry out high-quality work and take steps, such as strategic planning, that make the goals and priorities of your organization clear.
- Recognize that collaborative activities may require a time investment and some organizational resources.
- Remember, networking and collaboration can only go so far in the absence of new resources. Once new resources are obtained, work to ensure that the funds continue to be available.

For more information, contact: Mauricio Palacio, Hepatitis C Coordinator, Colorado Department of Public Health and Environment, at 303/692-2674 or Mauricio palacio@state.co.us and Kathy Jensen, Director, Information and Community Outreach, Hep C Connection, 720/917-3960or kjensen@hepc-connection.org.

#### 5. Look to the Long Term

Once you have a healthy process of community involvement, consider these steps for sustaining community support for the process.

- Identify New Stakeholders. As you work to integrate hepatitis services, in all likelihood you will encounter more individuals and organizations with an interest in the issue. Be sure to have a strategy for incorporating new stakeholders into the process on an ongoing basis.
- *Train Stakeholders*. The quality of a process depends greatly on participants' expertise. While each of the participants will have expertise in a specific area, they can always enhance their knowledge in other areas. Training does not have to be highly structured or intensive. Consider putting aside time at advisory council meetings where participants can learn more about hepatitis in their community. For example, various service providers can make presentations about their services, outreach workers can speak about their work in the field reaching at-risk populations, the health department epidemiologist can present surveillance data, and people with hepatitis can talk about what it is like to live with the disease. Another idea is to ask participants who attend national conferences to give summaries of workshops they found valuable.
- Communicate With Stakeholders. Keep people informed of the process and efforts to integrate services. People are more likely to remain engaged in a process if they have ongoing information about it. Consider using various communication tools such as list-serves, chatrooms, Web sites, and newsletters to keep participants up to date.
- Avoid Burn Out. Those participating in the process over time are in danger of experiencing burn out. While asking people to attend occasional

People are more likely to remain engaged in a process if they have ongoing information about it. meetings may not seem like a huge demand, on top of all the other responsibilities they have, it can become a burden. Consider the following steps to minimize the possibility of burn out.

- Show appreciation. Never underestimate the value of thanking people for their efforts. A little gratitude goes a long way. Consider holding an annual appreciation luncheon and recognizing ongoing participation in some way (certificates, etc.).
- Rotate responsibilities. Are the same people always chairing meetings and volunteering for taskforces? Distributing work among participants reduces the likelihood that people will be overwhelmed by the responsibilities.
  - Provide opportunities for feedback. Any process can be improved. Making sure that participants have opportunities to provide feedback about the process can lead to a more streamlined and efficient use of time and energy.
  - Provide Capacity-Building TA for Service Providers. Service providers who are asked to assume new responsibilities may need capacity-building technical assistance to facilitate the incorporation of those activities. Health department staff or other service providers in the community may be able to provide this assistance. Otherwise, look to other sources of technical assistance, such as the CDC, NASTAD, or other national organizations.

#### • Identify New Resources.

Seeking out additional resources should be an ongoing effort. While integration of services is an effective strategy for delivering services with few resources, your community will likely always have a list of needed services that cannot be established or expanded unless new resources become available.

### Capacity-Building Resources

### CARE Act Technical Information and Education (CATIE) TA Library

This online, searchable library contains resources on a variety of topics including needs assessment, planning, and working with affected communities (conflict of interest, roles and expectations for advisory committee members).

http://hab.hrsa.gov/CATIE/

#### Center for Community-Based Health Strategies, AED

The Center has numerous resources, including fact sheets and reports on viral hepatitis and technical assistance documents. http://www.healthstrategies.org/

#### HIVAIDSTA.ORG

This Web site, a project of NASTAD and the Academy for Educational Development (AED), provides TA materials for HIV prevention community planning groups (CPGs). Included are resources on assessment, planning, and meeting facilitation. http://www.hivaidsta.org

#### **Advocacy in Action**

Few identify IDUs as individuals who wield significant political power.

While substance abuse is often on the radar screens of local policymakers, their perspective, which usually focuses on ridding neighborhoods of drugs and reducing crimes associated with drug use, rarely focuses on the needs of drug users and those in recovery. Yet the Recovery Association Project (RAP), which was formed by recovering addicts in 1999 in Portland, Oregon, has succeeded in working with elected officials and other community players. These efforts resulted in the initiation of an array of services and activities responsive to the needs of RAP's members.

RAP is dedicated to providing a vehicle for people in recovery to speak out on substance abuse—related issues. Many people in recovery participate in 12-step programs, but these programs are focused on recovery and do not have community education or advocacy components. RAP was organized to provide people in recovery with a separate platform to publicly speak about recovery and drug-related issues. Initial efforts were funded through a Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Substance Abuse Treatment (CSAT) grant for community organizing.

"We started out by talking to people. We're big on talking," says Bruce Tyberg, one of RAP's founding members. "We found that many IDUs had hepatitis C but did not have any information about the disease. Even their doctors couldn't give them information. People were frightened of it. They thought they were going to die."

At the same time, a very high number of deaths in Multnomah County were caused by heroin overdose. Hepatitis C and overdose prevention became two major priorities for RAP. After determining the needs of their members, RAP took these concerns to the county commission. At a public meeting, RAP asked the commission to form taskforces on these two issues, made up of RAP members and staff from the Multnomah County Health Department (MCHD).

At the direction of the county commission, the two taskforces were formed, and roles, deliverables, and timelines were established. The taskforces developed sets of recommendations addressing the issues. The taskforce structure was extremely important in the final, successful outcome of the process. RAP was an equal partner in the process and was empowered to push for the needs of their community and be a significant voice in program design. MCHD provided the public health expertise, both administrative and technical

Once the recommendations were developed, RAP organized a public meeting that was attended by all the key players: county commissioners, MCHD, state agencies, law enforcement representatives, and RAP members. RAP leaders and members gave testimonials, and then the recommendations of the two taskforces were presented. The County Commission agreed to implement the recommendations.

MCHD was provided with funds to establish the hepatitis-C-related services identified by the taskforce, including outreach to affected communities, training for service providers (doctors), and testing of high-risk populations. Also, several activities were initiated to address heroin overdose.

These included posters warning inmates about the risk of heroin overdose (19 percent of overdose victims got out of jail less than 60 days before they died), medical authorities instructing doctors to be wary of prescribing benzodiazepine to patients with a history of drug abuse (mixing heroin with this drug increases the risk of overdose), and instructing outreach workers at detox centers and needle exchange sites to reassure IDUs that they would not be arrested if they call 911 in the event of an overdose. By 2000, overdose deaths dropped by 36 percent.

"By being prepared and organized," says Gary Oxman, MD, MCHD Health Officer, "RAP arranged the interaction between elected officials, the bureaucracy, and community members. RAP was instrumental in creating awareness among elected officials, legitimizing the need for the hepatitis C and overdose prevention services, and, ultimately increasing services."

From RAP's perspective, the health department was the only entity that could address the problem. "We can see the problems," Tyberg says, "but they have the expertise and the procedures for addressing them."

The process that RAP used to gain support for their priorities resulted in what many of those involved saw as an "everyone wins" outcome. The county commissioners could respond to community needs with concrete services, specific needs that RAP members had expressed to the organization's leadership were addressed, and MCHD received new resources to implement appropriate public health approaches.

While the end results of the process were positive for all involved, RAP's initial activities did result in some concerns for MCHD. Some health department staff were nervous about RAP's advocacy efforts, fearing a loss of their professional power and control. They were also concerned about criticism of their programs, feeling the community was "beating them up." Fortunately, the taskforce process that RAP established ensured that all parties had a voice in developing proposed programs.

"Some staff were concerned that we could not control the process," says Oxman. "We were very happy with the end product and learned that CBOs may appear intimidating, but they really are essential partners."

Oxman also stressed the importance of recognizing the priorities of community advocates. Heroin overdose issues were very important to RAP. If MCHD had refused to work with the organization on this issue, RAP may have backed off, and there may not have been a hepatitis C program.

Oxman also stresses that all the benefits resulting from the efforts of community advocates may not be immediately evident. As a result of the hepatitis-C-related services in place, funded by the County, MCHD has been well-positioned to seek out additional funding to expand their hepatitis C-related activities.

For more information, contact Gary Oxman, MD, Multnomah County Health Officer, at 503/988-3674 or gary.l.oxman@co.multnomah.or.us.

#### The Benefits of the Internet

The Internet has played an important role in the activities of many health departments and CBOs as they develop viral-hepatitis-related services. Using the Internet can be an effective way to reach diverse audiences with targeted information. While developing and maintaining a Web site does require resources and technical expertise, it can be highly cost effective in the long run. Agencies have used Web sites to:

- Post documents, such as strategic plans, for download, which saves printing, handling, and postage costs;
- Maintain and update calendars of events, support group schedules, and other time-sensitive materials; and
- Provide links to other Web sites that connect viewers with a broad range of information on treatment, support services, and other topics.

The Hep C Advocate Network (HEPCAN), a nonprofit, national organization based in Texas, has developed an extensive Web site to educate people across the country about viral-hepatitis-related issues. Advocacy activities are a major focus of the site. Included is information on what legislation is pending at the national and state levels, how the legislative process works at the federal level, and how to contact legislators. The site also includes state-by-state information on Medicaid, discussion of funding for hepatitis services, training information, and updates related to hepatitis. The site is interactive. Viewers can submit questions and comments, provide information on advocacy activities in their state, and sign up for the organization's list-serve. To view the Web site, go to <a href="http://www.hepcan.org">http://www.hepcan.org</a>.

In addition to the use of Web sites, many CBOs and health departments rely on e-mail to communicate with collaborative partners and clients. For example, in New Mexico, the health department found that e-mail was an effective way to remind people to come back for their hepatitis A and B vaccine doses. E-mail works even with homeless individuals, since many access e-mail accounts at the public library.

E-mail is also being used to communicate with individual clients as well as groups through list-serves and chatrooms. Newsletters and action alerts can also be distributed by e-mail.

### Beyond Your Community

While the work is done at the local level, the reality is that the bulk of the resources needed to carry out the work come from the state or federal government. Integration can only go so far. This health crisis is of such a magnitude that new resources will be needed at some point to meet the demand for services.

To some degree, it is the job of health departments to educate policymakers. Policymakers naturally consult with health directors and their staff about specific health issues, as they are the local public health experts. As public employees, however, there are limits on the extent to which state and local health department staff can become involved in advocacy. Extensive advocacy activities can appear to be a conflict of interest or possibly be perceived as a misuse of public funds.

It is the role of the community, CBOs, and af-

Nothing will win support as effectively as people who are affected by viral hepatitis sharing their stories and presenting their perspective on what is needed to address the issue fected populations, for the most part, to take the lead in advocacy efforts—to convey to policymakers the "will of the people." However, many or the basic activities of public health, such as surveillance, planning, and community organizing, are very important to advocacy efforts. Surveillance data can help advocates tell the story of who is affected and how the problem is growing in the community. Planning activities that identify service gaps allow advocates to communicate what is needed to address the problem. Community organizing can bring together those with an interest in the issue

Another way state and local health departments can communicate with policymakers is through national member organizations, like NASTAD, that represent state and local health departments and advocate on issues important to their constituents. These organizations include the Association of State and Territorial Health Officials (ASTHO) and the National Association of County and City Health Officials (NACCHO). Consider becoming involved with these national organizations if you are not already working with them.

#### **How Advocates Can Convey Their Message**

While it is up to the community to communicate their needs to policymakers, a little coaching may be in order to help them be more effective. The following are some general rules for effective advocacy by community organizations and affected populations.

Let Affected Populations Tell Their Stories
 At the most basic level, politics is about people. Making a case with data and reports is important, but nothing will win support as effectively as people who are affected by viral hepatitis sharing their stories and presenting their perspective on what is needed to address the

issue. Making a personal connection with policymakers may result in their taking an interest in the issue.

#### Develop a Broad Base of Support

Policymakers are concerned about keeping their constituents happy. When making decisions, they often carefully weigh how many people will be in support of their actions and how many will be disappointed since, come election time, these sentiments may translate into votes. A diverse group of stakeholders advocating on an issue can demonstrate that the issue has broad support within a community—making it more appealing for policymakers to support it.

#### Know What Is Needed

To generate interest, advocates need to be able to present the issue in a compelling way. However, this is just half the story. Advocates also need to be able to articulate, clearly and simply, what actions policymakers need to take to address the issue. For example, when asking for more funds, advocates need to tell what services are needed, how much money is required, and how the funded services will address the need within the community.

#### Coordinate the Message

Everyone involved in the advocacy efforts must ask for the same thing. Efforts should be coordinated among stakeholders. For example, in an effort to increase Congressional funding for state-level hepatitis programs, advocates should come to agreement on appropriation numbers so that congressional staff are not inundated with different groups asking for different things.

- Ask for Something That is Deliverable
  Before you embark on advocacy efforts, do
  your research. Advocates must ask for something that policymakers can actually deliver.
  You don't want to ask a member of Congress
  to act on something over which Congress has
  no jurisdiction.
- Follow Up With Policymakers
   Once you have made contact with a policymaker, follow up regularly. Let them know the impact of their actions and what remains to be done. Cultivating support among policymakers can pay off over the years, especially if they take a leadership role on the issue.

#### **How to Communicate With Policymakers**

It's not only high-powered lobbyists who get their messages heard. In fact, most policymakers make a special point of providing access and responding to their constituents. Various ways of communicating with policymakers include:

- Writing letters;
- Making telephone calls or using e-mail and fax;
- Having meetings face-to-face (either at the local office or in the state capitol or Washington, DC); and
- Attending a community forum with the policymaker.

Also, building support among the general public can help to raise the issue with elected officials. Consider developing a media strategy that will make people more aware of hepatitis. This could include public service announcements as well as news stories that explore the impact of hepatitis in your community. Various resources on how to work with the media are listed in the resource section.

#### **National Hepatitis C Advocacy Council**



The National Hepatitis C Advocacy Council (the Council) is a coalition of patient advocacy organizations. The Council's goal is to develop a cohesive hepatitis-related strategy on such issues as research, education, legislation,

diagnostics, clinical trials, and fundraising. Currently, the Council has 21 members.

According to Council President Andi Thomas, a unified advocacy effort is critical because little has been done to increase the capacity of the existing service infrastructure to provide hepatitis services. It wasn't until 2003 that the first hepatitis-specific legislation was introduced in Congress, Senate Bill 1143, "Hepatitis C Epidemic Control and Prevention Act." Given the number of people infected with hepatitis in the United States and the substantial costs that will result in providing medical care to these individuals, it is imperative that more federal resources be made available. Advocacy efforts will likely be instrumental in bringing this about.

The Council works to coordinate the advocacy efforts of its members and to promote advocacy on the part of individuals. The Council's Web site provides information on pending legislation, and a list-serve periodically distributes "Action Alerts" and updates to the hepatitis community and concerned individuals. Also, Council members individually take on legislative issues within their own states and local communities. The Council supports these activities by providing technical assistance and by serving as a forum for sharing ideas and strategies. Andi Thomas credits Council members' efforts with an increase in awareness at the state and local level, leading to the rise of advisory councils, strategic planning processes, and other activities that give the hepatitis community and affected individuals a voice.

An important part of the Council's work is bringing together various elements of the hepatitis community so that it can "speak with one voice." However, Thomas also acknowledges that more outreach is needed to broaden the constituent base. Community members may also need to be educated on effective strategies for enhancing and increasing hepatitis services. For example, some are resistant to integrating hepatitis services with HIV/STD services. Given the limited resources available for hepatitis, integration with HIV/STD services is viewed by many as one of the only viable approaches. By educating those within the hepatitis community and working to expand the community, the Council can further strengthen the message.

An additional goal of the Council is to provide technical assistance to build the capacity of local patient advocacy organizations. However, resources are not available to support activities in this area. In the future, the Council would like to be able to provide capacity- building support. For example, it could assist in developing resources for organizations, to eliminate the need for each to reinvent the wheel, and also take the lead in developing standard outcomes for various services to facilitate evaluation across organizations. Information on how to start a patient support group is available from the Council.

For more information on the National Hepatitis C Advocacy Council, go to: http://www.hepcnetwork.org.

#### **Advocacy Resources**

#### **Pending Legislation**

#### **American Liver Foundation**

Posted on their Web site is information on pending legislation at the national and state levels and reprints of testimony. http://www.liverfoundation.org

#### **National Hepatitis C Advocacy Council**

This Web site includes the text of pending legislation, along with a list-serve for action alerts and updates.

http://www.hepcnetwork.org

#### Sample Letters and Other Advocacy Aids

#### HepatitisActivist.Org

HepatitisActivist.org hosts a Web site that includes sample letters on various topics (increased funding, research, organ transplant) and has an Automated Congressional E-mailer (ACE) System that allows people visiting the site to send an e-mail directly to their members of Congress. http://www.hepatitisactivist.org

#### **General Resources**

### Changing Times, Continuing Needs: An Overview of HIV/AIDS Policymaking and Programs at the Federal Level

A NASTAD legislative primer on HIV/AIDS http://www.nastad.org/publicpolicyresources/legprimer.pdf

#### **Library of Congress: Thomas**

A searchable Web site with legislative information, such as the status of bills, committee information, and *The Congressional Record*. It also provides information on Congress, including how laws are made. http://thomas.loc.gov/

# 7

An Overview of

# Hepatitis C Care and Treatment

# An Overview of Hepatitis C Care and Treatment

integrated into services at San Diego County's STD clinics in September 1999 and expanded to the primary HIV counseling and testing site about a year later. Screening is offered to at-risk individuals. based on a risk assessment completed by the client or a counselor interview. For those who test HCVpositive and do not return to get their test results, a disease intervention specialist is assigned to the case for follow up. About 80 percent of clients who test HCV-positive receive their results. This is a significant accomplishment, given the hard-to-serve nature of the target population. Clients are primarily men, aged 20 to 45 years old, often with a history of substance use, unstable living situations, and no access to medical care.

When HCV-positive clients receive their test results, they receive counseling, focused on behavior change to reduce high-risk activities. They also receive information on how they can protect their health (e.g., limit or stop drinking alcohol, obtain a medical evaluation). Clients are also given a referral packet with general information on hepatitis A, B and C; a resource list of testing sites, health care providers, community-based clinics, clinical trials, support groups, and hepatitis-related organizations; and a glossary of related terms. Hepatitis A and B vaccinations are available to clients at the sites where HCV testing is available.

As with many health departments across the country, services end there. For clients who do not have private health insurance—which is the case for most of those who visit a public clinic—no resources are

available to provide health care in a coordinated way. San Diego County does not have a public hospital but does provide funds to community-based providers to

This document explores medical treatment and other services that are available currently for people living with hepatitis C. In addition, the efforts of two health departments, are profiled: the MA Department of Health's provider education program and California's Marin County treatment and case management program.

deliver health care services free of charge or on a sliding scale. But, bottom line, HCV-infected clients confronted by this chronic and serious condition are on their own for obtain-

ing the medical evaluation needed and any subsequent treatment indicated.

The challenges faced by San Diego County are not unique. Across the country, many health departments provide HCV testing to at-risk individuals. Unfortunately, clients who test positive for HCV have few, if any, options for further care. Some providers have argued that screening clients for HCV infection is pointless if those who test positive cannot be linked to medical services. Most agree, however, that clients need to know their HCV status. Data suggest that if clients know their HCV status, they are more likely to take steps to protect their health, such as limiting their intake of alcohol. They can also adopt safer behaviors that can prevent the spread of HCV to others.

Why are so few resources available to provide services to HCV-infected individuals? The federal government does not provide any funds to state and local health departments specifically for treating HCV. Categorical funding by the federal government addresses many related conditions, such as HIV, STDs, and substance abuse, but in most cases these funds cannot be used for HCV screening, evaluation, or treatment.

#### **Diagnosis and Beyond**

When persons are diagnosed with HCV infection, they might not immediately need treatment for the disease but they do, ideally, need to be under the care of a medical professional. Many HCV-infected people are asymptomatic, and subsequent medical evaluation does not always result in treatment. However, even without treatment, other steps can be taken to protect an HCV-infected person's health. These include:

- Screening for hepatitis A and hepatitis B infections and vaccination if they have not already been infected
- Testing to evaluate for chronic liver disease, which should be conducted regularly (patients with chronic active HCV infection and not on treatment should monitored twice a year)
- Providing referral to drug treatment if they are using illegal drugs
- Eliminating or reducing alcohol consumption and providing referral to alcohol treatment programs, if needed

People living with HCV may also need emotional support. Support groups, some with a specific focus, can help the newly diagnosed and also provide ongoing assistance in managing the disease.

Finally, newly diagnosed individuals should be counseled in how to prevent infecting others. For those who are active injection drug users, counseling should include how to adopt safer injection techniques. People with multiple sex partners should practice safer sex. HCV-infected individuals also should not donate blood, semen, organs, and other tissue or share toothbrushes, razors, or other personal care articles that might have blood on them.

The most effective treatment for Hepatitis C is a combination of interferon, an antiretroviral drug, and ribavirin.

#### Treatment of Hepatitis C

The most effective treatment is a combination of interferon, an antiretroviral drug, and ribavirin. Since 2001, pegylated interferon, which is long-acting and injected weekly, has been approved for treatment alone or in combination with ribavirin. Successful treatment can eradicate the virus. Treatment can also slow disease progression, improve histology, and reduce the risk of liver cancer. Combination therapy is most effective in patients with HCV genotypes 2 and 3, which represent about 25 percent of patients in the United States. The most common genotypes, 1a and 1b, which affect about 75 percent of patients in the United States, are currently considered to be the most difficult to treat.

Treatment is not recommended for all HCV-infected individuals with liver damage. Interferon should not be prescribed for people with serious psychiatric illness, unstable heart disease, or uncontrolled diabetes. Ribavirin should not be given to pregnant women and people with anemia, heart disease, stroke, or kidney disease.

Side effects of treatment can be severe, enough to cause some patients to stop treatment. Side effects from the two drugs include anemia and other blood disorders, heart disease, birth defects, depression, anxiety, insomnia, headache, fatigue, nausea, and muscle and joint aches. Severe side effects from interferon, which are rare, include thyroid disease, depression with suicidal thoughts, seizures, acute congestive heart and renal failure, vision loss, and lung problems. The side effects tend to lessen over the course of treatment.

The goal of treatment is a sustained virologic response (SVR). Therapy is considered to be successful if HCV remains undetectable six months after treatment ends. For patients with HCV genotype 1, the response rate to one year of combination therapy

The NIH Consensus Statement for the Management of Hepatitis C - 2002 was developed by an independent, non-advocate, non-Federal panel. The consensus meeting was convened to provide an update on a 1997 conference on the same topic. The 2002 Consensus Statement expands the scope of patients eligible for treatment to include those who use injection drugs, consume alcohol, suffer from co-morbid conditions such as depression, or are co-infected with HIV. The consensus statement addresses:

- Natural history of hepatitis C
- Appropriate approaches to diagnose and monitor patients
- Effective therapy for hepatitis C
- Which patients with hepatitis C should not be treated
- Recommendations that can be made to patients to prevent hepatitis C transmission

The consensus statement is available online at: http://consensus.nih.gov/cons/116/116cdc intro.htm.

The American Association for the Study of Liver Diseases (AASLD), an association representing more than 2,400 physicians, researchers, and allied hepatology health professionals dedicated to advancing the science and practice of Hepatology, has also published practice guidelines on the diagnosis, management, and treatment of hepatitis C. These guidelines are available under the "Practice Guidelines" section of AASLD's Web site at <a href="http://www.aasld.org">http://www.aasld.org</a>.

#### Other Treatment Resources

#### **Treatment**

Hepatitis Foundation International, http://www.hepfi.org/pages/liv\_diagnosis.html

HIVandHepatitis.Com, http://www.hivandhepatitis.com/

National Institute of Allergy and Infectious Diseases, http://www.niaid.nih.gov/dmid/hepatitis/default.htm

#### Research

Hep C Research.com, http://www.hepcresearch.com/

#### **Clinical Trials**

Clinical Trials. Gov

This NIH site provides information about federally and privately supported clinical research, http://www.clinicaltrials.gov

CenterWatch Clinical Trials Listing Service, http://www.centerwatch.com/patient/studies/cat79.html

of pegylated interferon and ribavirin is 40 to 45 percent. Data are limited on patients with genotype 4, but current studies suggest that one year of combination therapy is also needed to achieve similar response rates as those for genotype 1. Eighty percent of patients with genotypes 2 or 3 can achieve SVR with six months of combination therapy. For those who relapse after initial treatment, re-treatment might be an option.

Almost one half of all liver transplants in the United States are a result of HCV-related liver disease. Reinfection of the transplanted liver by HCV occurs at a high rate, but second transplants are rarely required.

#### The Treatment Dilemma

Given the unpleasant side effects, the cost of treatment (an estimated \$10,000 to \$15,000 a year for drug therapy—treating liver failure can cost \$50,000 to \$250,000), and the limited efficacy, some care providers and their patients consider other options. Patients must carefully weigh the likelihood that the disease will progress with the benefits and risk of therapy, especially since the progression is highly variable and unpredictable. For example, in a recent study reported in the *Journal of the American Medical Association* (JAMA), Harvard researchers noted that 30 to 70 percent of infected individuals may never progress to cirrhosis before dying from other causes.<sup>1</sup>

Some HCV-infected individuals opt to explore alternative or traditional therapies. Milk thistle, for example, is a popular herbal remedy. Some people who are taking medication for HCV believe it reduces side effects. There is no evidence that herbal remedies are effective, and some may actually be harm-

<sup>&</sup>lt;sup>1</sup> Salomon JA, Weinstein MC, Hammitt JK, Goldie SJ. Cost-effectiveness of Treatment for Chronic Hepatitis C Infection in an Evolving Patient Population. *JAMA* 2003 290: 228-237.

ful. Patients should always consult their doctors before trying herbal therapies, since they can be toxic or react with other medications.

Another important consideration is that few HCV-infected individuals are candidates for interferon-based therapies. In a study conducted at a county teaching hospital in Cleveland, Ohio, 72 percent of patients with HCV infection did not receive antiviral therapy because of failure to show up for appointments or tests (37 percent), severe co-morbid medical or psychiatric illness (34 percent), ongoing alcohol or drug abuse (13 percent), or preferences against treatment (11 percent). Another 28 percent of patients were treated, and 13 percent of these had a sustained viral response. Researchers concluded that most patients with HCV infection are not candidates for antiviral therapies, and alternative interventions should be sought for them.<sup>2</sup>

Providers are encouraged to make treatment decisions on a case-by-case basis.

These data are important to consider when weighing the advantages and disadvantages of implementing a treatment program for HCV-infected clients. Many medical clinics, correctional facilities, and hospitals are concerned that providing treatment services will bankrupt their program. In fact, numerous data, such as those in the study mentioned above, suggest that only a small percentage of clients would be eligible or willing to begin treatment, indicating that the costs of treatment could be manageable.

However, a growing number of studies are finding that many of these "ineligible" patients can be effectively treated if appropriate precautions are taken and if adequate supports for the patient are available. As this field continues to evolve and as HCV therapies rapidly improve, providers are encouraged to make treatment decisions on a case-by-case basis.

<sup>&</sup>lt;sup>2</sup> Falck-Ytter Y, Kale H, Mullen KD, Sarbah, SA, Soerscu S, McCullough AJ. Surprisingly Small Effect of Antiviral Treatment in Patients with Hepatitis C. *Annals of Internal Medicine* 2002 136: 288-292.

#### Care for the Uninsured and Underinsured

Some options are available for providing health care to people who lack or have insufficient private health insurance. However, not everyone is eligible for these programs.

#### Medicaid

As the nation's major public health insurance program for low-income Americans, Medicaid finances health and long-term care services for 47 million people. The program is intended to cover the poorest and most vulnerable populations. It is often the only source of health insurance available for 35 million children and parents, and it provides acute and long-term care for 8 million people with disabilities. It also assists over 6 million low-income seniors and individuals with disabilities who receive Medicare.

To qualify for coverage, an individual must meet financial criteria and be a member of a "categorically eligible" group, such as low-income children, pregnant women, parents, the elderly, and people with disabilities. While federal law mandates coverage for some groups below specified income levels, states can extend eligibility beyond these minimum standards. As a result of this flexibility, coverage varies significantly across states.

States are required to provide certain services, including inpatient and outpatient hospital services, and receive federal matching funds for additional, optional services such as prescription drugs and clinic services. States also receive supplemental Medicaid payments to aid hospitals serving indigent patients.

State Medicaid programs face significant challenges, given the current fiscal crisis facing most states. Medicaid costs continue to rise, 13 percent in FY 2002, at a time when most states face huge budget deficits. States are limiting prescription drug spending, have frozen provider payments, and are reducing benefits and limiting eligibility.

For more information, visit the Centers for Medicare and Medicaid Services (CMS) web site at http://cms.hhs.gov

#### Ryan White CARE Act

The federal Ryan White CARE Act provides health care for people with HIV disease. Enacted in 1990, it fills gaps in care faced by those with low-incomes and little or no insurance. The Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau administers the program through hundreds of grantees, who serve 533,000 people each year.

The CARE Act includes four titles, and states are responsible for administering Title II. Title II funds assist states and territories in improving the quality, availability, and organization of health care and support services for individuals and families with HIV disease. The AIDS Drug Assistance Program (ADAP) is also funded under Title II. ADAP provides medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid.

Individuals who are co-infected with HIV and hepatitis can be treated under the CARE Act, as long as they meet the eligibility requirements, which vary from state to state.

For more information, visit the HRSA HIV/AIDS Bureau Web site at <a href="http://hab.hrsa.gov">http://hab.hrsa.gov</a>, or visit NASTAD's Web site at <a href="http://www.nastad.org/">http://www.nastad.org/</a> res\_public\_policy.asp?menu=res. Click on "Funding Profile" listed under the "State Federal HIV/AIDS Funding Profiles." A copy of the AIDS Drug Assistance Program (ADAP) Monitoring Report can also be viewed at <a href="http://www.nastad.org/ADAP/">http://www.nastad.org/ADAP/</a>.

#### The Veterans Health Administration

The Veterans Healthcare System, which serves eligible U.S. veterans, offers hepatitis C screening, treatment, and supportive services to its patients. Visit <a href="http://www.hepatitis.va.gov/">http://www.hepatitis.va.gov/</a> for more information on the VA's hepatitis C program.

#### **Indigent Care**

Indigent care programs are available in some communities. In most, these constitute a public hospital or programs carried out by community-based programs, such as programs providing care to homeless individuals. These programs are often not designed to provide the kind of ongoing care a person with chronic hepatitis needs.

#### Resources on the Uninsured and Underinsured

#### Kaiser Family Foundation

KFF's supports the Kaiser Commission on Medicaid and the Uninsured, which studies the challenge of providing health care to those without coverage. http://www.kff.org

**Treatment and Support Continuum** 

Combination therapy for HCV is expensive. For someone who is uninsured or underinsured, even the most basic care might be unaffordable. Some service providers, including state and local health departments, have been reluctant to promote hepatitis screening programs because of the lack of options for treatment if a person is infected. They argue that there is no point in telling a person that they are positive if follow-up medical care cannot be offered.

That argument overlooks opportunities to provide essential services to this population. While funding for many of the activities listed below might not be available now, these services should be considered as part of the continuum of care for people living with HCV. State and local health departments should explore ways to integrate these services, as much as possible, into services targeting populations at risk for HCV.

#### **Referral for Medical Evaluation**

For those who are HCV infected, regular tests to monitor the health of the liver are essential.

- Liver function tests are performed to measure
  the levels of enzymes and other substances.
  When the liver is inflamed or damaged, certain
  enzymes will be released or the level of some
  substances will change. Common liver function
  tests include albumin, total protein, the enzymes
  ALT and AST, alkaline phosphatase, and bilirubin.
  If these tests indicate liver damage, a liver biopsy
  should be performed.
- A *liver biopsy* is a diagnostic tool to determine the severity of liver disease and the stage or degree of fibrosis in patients who have hepatitis
   C. Before a biopsy, an ultrasound and/or a CT

For those who are HCV infected, regular tests to monitor the health of the liver are essential. scan may be performed. Ultrasound can assess the size, structure, and vascular supply of the liver. CT scans confirm the findings of ultrasound and, by measuring the size and texture of the liver, can be used to detect tumors. Biopsies can identify the site of a lesion and can also assess the degree of liver damage. The utility of a liver biopsy in patients infected with HCV genotypes 2 or 3 is currently a topic of debate. Because of the high likelihood of achieving SVR in these patients through combination drug therapy, many providers elect to bypass the liver biopsy and begin drug therapy without assessing the severity of liver disease.

 Other tests that should be provided during the initial medical evaluation include a complete blood count (cbc), a viral load test, and a genotype test.

Hepatitis C has been linked to many other medical conditions. Some are severe, especially during the later stages of liver disease, such as kidney damage and liver cancer. Case reports suggest that a number of autoimmune conditions might also be associated with hepatitis C. Medical conditions that have been linked to hepatitis C include Sjogren's syndrome, rheumatoid arthritis, vasculitis, thyroid disease, scleroderma, fibromyalgia, and type II diabetes. The severity of these conditions supports the importance of access to regular medical care for people living with hepatitis C.

#### Referrals for Other Services

People infected with HCV may also benefit from referral to other services. Hepatitis C disproportionately affects some populations, including current and former injection drug users, individuals who have been incarcerated, people with mental illness, and people of color. Some of these populations may live somewhat chaotic lives and face various challenges.

Persons with severe mental illness are 11 times more likely than the population at large to have HCV. Some programs, especially harm reduction programs such as syringe exchange, have found that screening for hepatitis can provide a "point of access" to this population. Many people at risk have sought out screening, having heard of the risk of HCV. Others have been identified when they accessed services, such as STD services. Their engagement in care can provide an opportunity to link them to other services.

Most importantly, people with HCV should be referred to substance abuse treatment if they are still using drugs or need treatment for alcohol abuse. If people are still injecting drugs, they can be exposed to other blood-borne viruses such as HIV and hepatitis B virus or they can get re-infected with HCV. Since alcohol can accelerate liver damage in people with HCV infection, those who are infected should reduce or abstain from alcohol use. For those who are addicted, alcohol reduction or cessation may not be possible without treatment.

Persons with severe mental illness are 11 times more likely than the population at large to have HCV.<sup>1</sup> Their mental illness might affect their ability to access treatment. These individuals should be linked to appropriate services for their condition.

<sup>&</sup>lt;sup>1</sup> Rosenberg SD, Goodman LA, Osher FC, Swartz MS, Essock SM, Butterfield MI, Constantine NT, Wolford GL, Salyers MP. Prevalence of HIV, Hepatitis B and Hepatitis C in people with severe mental illness. *Am J Public Health* 2001; 91: 31-37.

#### **Treating HCV in People with Mental Illness**

The high prevalence of HCV in people with mental illness is a serious challenge for health care providers. Hepatitis C treatment is associated with significant mental-health-related side effects, for which people with a history of mental illness, including substance use, may be at increased risk. Treatment options currently available, interferon monotherapy and interferon and ribavirin combination therapy, can result in serious psychiatric side effects including psychosis, depression, suicide, and substance use relapse.

Early treatment guidelines, developed in 1997 by an NIH consensus panel, recommended that people with mental illness and those who continue to use illicit substance not be offered treatment for HCV. This recommendation stemmed from the belief that substance users were more prone to adherence lapses and that the psychiatric side effects posed too great of a threat to people with mental illness. The treatment guidelines were revised in 2002, and treatment is now recommended for people with mental illness and for active drug users.

Studies have indicated that between 40 to 80 percent of drug users adhere to treatment, with the type of illicit drug used and the regularity of use being major determinants for adherence. Other factors can also play a role in adherence. People with mental illness and illicit drug users may have chaotic, unstable lives with many challenges. Inadequate social support and housing can affect adherence. Factors that can enhance adherence include the quality of the clinician-patient relationship, the treatment regimen, clinical setting, and the treatment of co-morbid conditions such as mental illness and substance abuse.

Other populations affected by HCV might be poor and unfamiliar or distrustful of the mainstream health care system. Linking them to necessities, such as food and housing, might help to build their confidence in "the system" and serve to link them to a range of services. If they do not already have access, linking people to health coverage, such as Medicaid, is also crucial.

Individuals with a history of incarceration are also disproportionately affected by hepatitis C. These individuals might benefit from a range of services including housing, employment, and legal aid. Those who are still incarcerated might be in need of discharge planning services that link them to services outside of the correctional facility.

#### **Secondary Prevention Services**

Once a person is infected, secondary prevention measures prevent or slow disease progression. People with HCV infection can take two significant steps to protect their health.

#### Get vaccinated

Since hepatitis A and hepatitis B can exacerbate hepatitis C, people infected with HCV should be screened to determine if they have been exposed to hepatitis A or hepatitis B. If they have not already been infected, they should be vaccinated for both. The hepatitis A vaccine is given in two doses, 6 to 18 months apart. The hepatitis B vaccine is usually given in three doses over a sixmonth period. Follow-up is often needed to ensure that all doses of the vaccines are received.

Cease or reduce consumption of alcohol
 People with HCV should ideally abstain from
 alcohol use, since consumption of alcohol can
 speed the onset of liver disease. If a person
 cannot stop using, any reduction in alcohol use is
 beneficial. Individuals with drinking problems
 may need to be referred to substance abuse
 treatment programs.

People living with HCV should also be educated about other steps they can take to protect their liver. They should consult with a physician or pharmacist when taking prescription or over-the-counter medications, since many drugs are metabolized in the liver. Ibuprofen and acetaminophen in large doses can harm the liver. Following a healthy diet and reducing stress are also important. Some people living with HCV explore alternative therapies.

#### **Supporting the Adoption of Safer Behaviors**

People infected with HCV should be counseled on how to prevent transmitting the virus to others. This is especially important if the person continues to inject drugs. Numerous resources are available that discuss safer injection practices. While injection drug use is the main transmission mode, HCV-infected individuals should also be educated about other means of exposure, such as household, sexual contact, and occupational exposure.

#### **Support Groups**

As with many life threatening illnesses, people living with HCV might want to share their experiences with others who are confronting similar challenges. Support groups, often conducted by organizations by and for people living with HCV, are available in various communities across the country. Many of these groups are run by volunteers with extremely limited resources. Depending on the resources available and the size of the community, an array of support groups might be tailored to meet the needs of various populations such as those who are infected but asymptomatic, are in treatment, or are treatment nonresponders.

Support groups can play a key role in maintaining the health of people with HCV. Peers can help support people in abstaining from alcohol and can provide comfort when they are experiencing the unpleasant side effects of treatment. Knowing that someone else has gone through what they are going through can be an ongoing motivator.

#### **Case Management**

As has been learned from the HIV epidemic, case management can make a significant difference in

### **Massachusetts: Multiple Approaches for Educating Providers about HCV**

Imagine being diagnosed with a life-threatening illness and then, when you go to the doctor, finding that he or she knows as little about the condition as you do. State and local health departments regularly hear from frustrated people living with HCV that providers know little about how to evaluate and treat HCV infection. In response, many health departments have initiated programs to educate health care providers about HCV. As with other HCV-related needs, funds to carry out these activities are extremely limited.



In 1999, when the Massachusetts Department of Public Health (MDPH) initiated a viral hepatitis program, educational activities targeting health care providers were a major component. Materials were developed for health care providers over several years. These included an educational audio tape for primary care providers, a pocket-sized HCV screening algorithm for primary care providers, a manual on integrating hepatitis C into HIV services, posters, and a resource mailing to nursing professionals containing basic information on HCV and strategies for talking to patients about drug use and sex. MDPH also has held several one-day, regional conferences for providers. All these efforts are financed by state funds.

In developing the materials, MDPH took several steps to ensure that they addressed the needs of the target population. Focus groups were conducted to determine what information providers would find most valuable, and business reply cards were included with many of the resource mailings. MDPH also formed the Hepatitis C Advisory Committee, made up of various stakeholders including organizations representing health care providers. The advisory committee provides ongoing advice to MDPH.

Using multiple approaches, both the written materials and the conferences, provides flexibility and enables MDPH to reach a wider audience, since people prefer different education methods. For example, MDPH is revising the surveillance process for HCV—providers will now report cases, instead of local health departments—and MDPH is planning a series of conferences for the coming year that will educate providers about the new reporting requirements. Conferences enable MDPH to provide information in a timely way. Publications can quickly become dated, and funds may not be available to update publications as new issues arise.

Reaching health care providers, especially physicians, can be challenging. Even when CME credits are provided, getting physicians to attend can be difficult due to the demands on their time. Also, physicians are inundated with information. In their formative research, MDPH learned that the appearance of documents targeting physicians is very important. To be noticed, materials must be designed and printed well. Unfortunately, producing this type of document is expensive.

Primary care providers in particular are a key target audience for MDPH. MDPH has found that many primary care providers do not identify HCV as an issue that they need to address. Their approach to patients with HCV has often been to refer them to a specialist, rather than manage the illness themselves.

MDPH has found that it is often easier to reach nursing professionals and physician assistants, who may have more time for patient education efforts. Central to MDPH's efforts in reaching nursing professionals is a focus on occupational exposure. MDPH's research found that nursing professionals felt very vulnerable to HCV and wanted more information on how to protect themselves in the workplace.

Despite their efforts, MDPH continues to hear from consumers and advocacy groups that more provider education is needed. According to Dan Church, Hepatitis C Coordinator for MDPH, providers need to be educated on an ongoing basis—to reach the broadest provider audience and to keep providers updated as information changes. Better surveillance data are also needed to document the impact of HCV. Currently, many providers may not recognize the problem and therefore, do not feel a need to respond. Unfortunately, funding to enhance surveillance efforts is limited.

An important part of provider education is involving people living with HCV. MDPH works to educate patients so that they can encourage their providers to learn more. An MDPH-developed video and supplemental booklet for newly diagnosed individuals includes a list of questions that patients should discuss with their physicians. This way, patients at least know what questions need to be addressed, making the education process more efficient for the provider and highlighting the issues raised.

For more information on the Massachusetts Department of Public Health program, contact Dan Church, Hepatitis C Coordinator, at 617/983-6800 or Daniel.Church@state.ma.us. For copies of the health care provider resources developed by the Massachusetts Department of Public Health go to: http://www.masshepc.org.

ongoing treatment of a chronic condition, especially for populations facing many challenges in their lives. These people are usually at increased risk of being lost to care because the task of accessing all the services they need, and the bureaucracy associated with doing so, can be extremely daunting, if not impossible. Case managers can assess what services are needed and help the client obtain these services. Through ongoing interaction with the client, the case manager can assess whether client needs are being met and can help address new needs as they arise. Case management can also help support adhering to treatment and adopting and maintaining safer behaviors.

Unfortunately, few case management models are available for treating HCV-infected individuals—primarily because of the lack of resources to develop and implement these services.

### Marin County: Integrating HCV Services Into an Existing HIV Program

Marin County is a small suburban county 30 minutes north of San Francisco. Although the per capita income is one of the highest in the country, 8.1 percent of Marin residents are without health insurance coverage. The County's Hepatitis C Program primarily serves those who are uninsured or underinsured and have the least access to health care.

Five years ago, the County of Marin Department of Health and Human Services initiated HCV screening activities linked with medical consultation services. These services were integrated into existing HIV/AIDS program. Integration into the HIV/AIDS program was the most logical choice, since it allowed the health department to build on existing infrastructure and staff resources, as well as established links with community-based providers. Because of limited resources, HCV services would not have been

possible if they were provided on a stand-alone basis. According to Craig A. Lindquist, MD, Medical Director of the Marin Specialty Clinic, "The greatest challenge is funding—HCV services will always be difficult to provide without dedicated funding for such services. To provide HCV services, you really need the commitment of the local health department and the local and state government. Hepatitis C must be recognized as a public health issue and made a priority in the community to bring the services needed."

#### Screening

The HCV Screening Program provides screening, risk-reduction counseling, testing, and referral of infected clients for medical evaluation. Integrating the HCV Screening Program into the county's HIV Testing and Outreach Program was the most logical and cost-effective approach to providing HCV testing and counseling. HIV counseling staff, already experienced in obtaining demographic and risk behavior data, facilitated HCV client referral to medical care. To prepare staff for incorporating HCV services, 12 hours of training were provided. Training included basic information about liver physiology, epidemiology, disease transmission of HCV, HCV-antibody testing, and HCV treatment. Counselors also received training in risk-reduction techniques for clients with ongoing risk behaviors and information on how HCV-infected clients can slow disease progression.

A risk assessment questionnaire specifically addresses HCV and collects data on demographics, possible HCV risk factors, and other information that can be used to counsel clients on protecting their health. The HCV-specific questionnaire facilitates the counseling sessions and decreases the time needed to perform HIV and HCV risk assessments. Test results are provided to clients at a scheduled follow-up appointment two weeks later, and reminder notices are sent to those who miss their appointments.

The program now provides outreach and on-site testing at more than 20 locations.

Initially, HCV testing was conducted once a week at the public health laboratory. Over time, the program has been expanded and now provides outreach and on-site testing at more than 20 locations, including residential drug treatment centers, homeless shelters, and locations where services are provided to high-risk populations such as drug users, the homeless, and the mentally ill.

Targeted HCV testing has been highly successful. From January 1999 to December 2002, 30 percent of clients tested by the program were infected with HCV. Of the clients who tested positive, 83 percent reported a history of injection drug use, and 45 percent reported injecting drugs within the past year.

#### **Specialty Clinic Services**

The Marin County HIV/AIDS Program provides medical care to HIV-infected clients at the county HIV/AIDS Specialty Clinic. Clients who test positive for HCV are referred to the Specialty Clinic's HCV Consulting Clinic. About two-thirds of the patients at the HCV Consulting Clinic are referred through outreach efforts. The remaining patients are referred by other providers in the community, including local medical providers, substance abuse treatment programs, homeless shelters, and the community-based family practice clinic that treats mostly Medicaid and uninsured patients. Other patients are self- referred.

HCV-infected patients have their first appointment with the HCV clinical coordinator, who compiles the patient's medical history, documentation of HCV infection, and any available lab results. Noninvasive tests including liver function, viral load, and ultrasound are administered. The clinical coordinator also provides basic HCV education and an overview of the clinical services. Given the complexity of the treatment, this overview increases patients' awareness of the process so that they are better prepared.

#### The Importance of Staff Training

All specialty clinic medical and nursing staff are trained in the evaluation and medical management of HCV through medical in-services with local hepatologists, attendance at HCV education conferences, and consultation with a tertiary carelevel hepatologist. Educational sessions cover management of HCV, extra-hepatic manifestations of HCV, recommendations for treatment of nonresponders or relapsers, HIV/HCV co-infection, and criteria for referral to transplant evaluation.

HCV infection is a complex disease to treat. Also, since HCV is an emerging disease, new information on treatment is continuous. Provider education must be ongoing, and time must be allotted for staff training.

Treatment is provided based on HCV treatment protocols and is coordinated by a treatment team, consisting of a nurse practitioner (NP) and the HCV clinical coordinator. The NP and the HCV clinical coordinator meet with the patient and describe the treatment process, train the patient in self-injection, and describe potential side effects and how to manage them. If complications result during treatment, the treatment team consults with the supervising physician.

### Linkage to Case Management and Primary Care

All patients are required to have an outside source of primary care, since the specialty clinic's HCV program does not have the capacity to provide this care. The HCV clinical coordinator assists patients with establishing primary care.

Before the first medical appointment, patients are referred to a social worker to assess their ability to pay for care. Patients who do not have some form of coverage, either private insurance, Medi-Cal, or the county's insurance, are referred to a case manager. The health department contracts with two community-based organizations (CBOs), an AIDS service organization and a methadone clinic, to provide these services. Case managers work with patients to determine their eligibility, help them apply for benefits, and educate them about HCV infection and treatment options.

The link to the CBOs is an important part of the program. These organizations serve as resources in

Patient education should be built into the process from the earliest stages. various areas and are experienced in working with the patient population. Given their existing ties to the patient population and the range of services that they offer, the CBOs are well-positioned to play a complementary role in the care provided by the specialty clinic's HCV Consultation Clinic. To ensure the ongoing availability of these services, the health department recognized the need to provide resources to support the CBOs' efforts. On the advice of the health department, the county's Board of Supervisors allocated funds to support the two contracts.

#### **Lessons Learned**

Staff identified a variety of challenges in the program's implementation and ongoing operation:

#### • Importance of HCV Patient Education

Patient education should be built into the process from the earliest stages. Patients not only need to know about the course of the disease, how to slow progression of liver disease, and how to prevent spreading the disease to others, but they also need to know about evaluation and treatment. Providing patients with information on what they can expect prepares them for future steps and limits the time that must be devoted to patient education in medical appointments.

#### Co-morbidity of Mental Health and/or Substance Use Issues

The population served by the specialty clinic presents with various mental health and substance use issues. Of the clinic's patients, 59 percent continue to drink alcohol after diagnosis, and 22 percent report having injected drugs within a year of being evaluated. Depression is the most common mood disorder, found in 71 percent of patients reporting a history of psychiatric disease. More severe psychiatric illness has also been reported. These co-occurring conditions can

significantly affect patient care, and staff must devote significant energy to move patients along in the evaluation process. Active drug use among patients is a serious issue. It requires links with community-based substance abuse treatment programs to facilitate the evaluation of chronic HCV infection.

#### • Medical Complexity of Patients

Many patients also suffer from other chronic diseases, such as hypertension or other cardiovascular disorders, smoking-related illnesses, and diabetes. These health problems were either known or identified in the initial evaluation, and patients were referred to care for these conditions. Additional evaluations can delay HCV treatment and in some cases, patients were lost to followup.

#### • Staff Communication

HCV infection is a complex condition to treat. The phlebotomist plays a key role in collecting information from the various staff and compiling it in the clinical folder. Since the evaluation process is already lengthy—multiple appointments over three to four months—all the information needed should be available at each subsequent appointment. Any breakdown can result in needless appointments, which may result in patients being lost to care. Ensuring that the process stays on track requires ongoing staff focus and communication.

For More Information: A detailed description of Marin County's HCV program is available in the *Journal of the Association of Nurses in AIDS Care*, Vol. 14, No. 5, Supplement to September/ October 2003, 95S-107S. Information is also available from Suzan Stringari-Murray, ACRN, MS, ANP, Marin County Health and Human Services, Specialty Clinic/HCV Consultation Clinic at sstringari@co.marin.ca.us or 415/499-7377.

# 8

Hepatitis A and Hepatitis B

# **Vaccines**

#### Hepatitis A and Hepatitis B Vaccines

accines to prevent hepatitis A virus (HAV) and hepatitis B virus (HBV) infections have been commercially available in the United States since 1995 and 1982, respectively. However, HAV and HBV infections continue to be among the most prevalent vaccine-preventable diseases.

Hepatitis B vaccination of infants is now a routine practice in the United States and recommendations for early adolescent immunization have resulted in school entry and 7th grade vaccination requirements in most states. Hepatitis A vaccination of children aged 2 years and older varies from state to state. Targeting children in areas where there have been historically high hepatitis A rates has been an effective strategy in decreasing the incidence of hepatitis A in the United States. However, there remain sizable numbers of unvaccinated older adolescents and young adults engaging in behaviors that put them at risk of both hepatitis A and hepatitis B. Increasing the number of at-risk adolescents and adults that are vaccinated could result in significant benefits for society. For example, CDC estimates that for every 1 million at-risk adults vaccinated for HBV:

- 50,000 new HBV infections are prevented;
- 1.000 to 3.000 chronic HBV infections are prevented:
- 150 to 450 deaths from cirrhosis and liver cancer are prevented; and
- \$100 million in future, direct medical costs (discounted) is saved.

Many people, both in the general public and in the health care community, associate vaccination programs with children. Other than annual flu vaccination campaigns, there are few vaccine initiatives targeting adults. Various challenges exist when attempting to vaccinate adult populations. Many adults do not seek preventive medical services for various reasons, whether it is the lack of health insurance or not wanting to take time off work. Therefore, they do not come into contact with practitioners who are focused on preventive medicine. At an infrastructure level, there are few adult vaccine tracking systems and no national surveillance for adult vaccine coverage, which

#### Who Should Be Vaccinated

#### Hepatitis A

- Injection and non-injection drug users
- Travelers to places with high rates of HAV infection (Africa, Central/South America, Asia, Middle East, Russia)
- Gay Men/Men who have sex with men (MSM)
- People with clotting-factor disorders (hemophilia)
- People with any type of chronic liver disease
- People waiting for or who have had a liver transplant
- Children living in areas of the U.S. with historically increased rates of hepatitis A

#### Hepatitis B

- All babies, at birth
- All children, aged 0-18 years old, who have not been vaccinated
- Injection drug users (IDUs)
- Sexually active heterosexuals (more than one partner in prior six months, recently acquired STD)
- Gay Men/MSM
- Sex contacts of people with chronic hepatitis B
- Household contacts of people with chronic hepatitis B
- People with jobs involving contact with human blood
- Kidney dialysis patients and patients with early renal failure
- Families of children with evidence of past infection who have been adopted from areas with high rates of HBV infection (Southeast Asia, Africa, Amazon Basin, Pacific Islands, Middle East)
- Those traveling or living internationally for more than six months in areas with high or intermediate rates of HBV infection
- Inmates in correctional facilities
- Clients and staff of institutions for the developmentally disabled

further complicates obtaining useful data on adult vaccination. Finally, there is an ongoing need to educate adults and their providers about vaccination. The lack of awareness on the part of both adults and providers creates a significant barrier when promoting the vaccination of at-risk populations.

### MISSED OPPORTUNITIES

Efforts are underway to reach adults at risk for HAV and HBV infections. However, many adults go unvaccinated because of a lack of resources and other reasons. At-risk adults account for more than 75 percent of all new cases of HBV infection each year.

Currently, public health initiatives to vaccinate at-risk adults are a bit like orphans. State and local health department immunization programs tend to focus on children; this has traditionally been their mandate from CDC, and federal immunization funds overwhelmingly support infant and children vaccine initiatives. Due to similarities in affected populations and means of transmission, HIV/AIDS and STD programs are increasingly responsible for administering viral hepatitis services. While these programs have the expertise to reach at-risk adults, sufficient resources have not been available to carry out comprehensive viral

hepatitis programs that include vaccination. In many areas, no one has really taken "ownership" over viral hepatitis services.

Non-traditional vaccination sites such as STD clinics, correctional facilities, substance abuse treatment centers, homeless shelters, HIV counseling and testing sites, and mobile outreach activities all provide opportunities to vaccinate adults at risk. Studies have found that over half of those newly infected with HBV have accessed services in public health settings, where vaccination could have also been provided. Of all individuals with reported acute hepatitis B, 37 percent reported prior treatment of an STD, 29 percent reported prior incarceration and 56 percent had been treated for an STD and/or incarcerated in prison or jail prior to their illness. Studies indicate that there is a 70 to 85 percent acceptance rate of the first dose of hepatitis B vaccine among IDUs and STD clinic clients, and at HIV counseling and testing sites and correctional facilities. Clearly, these populations are receptive to preventive measures and these settings represent missed opportunities for disease prevention.

There are various reasons why non-traditional sites do not offer vaccination. Vaccination programs require the purchase and storage of vaccine, infrastructure to deliver vaccine, provider and patient education, and evaluation. The allocation of additional resources would address some of these requirements but providers and staff must also understand the importance of vaccination. In a survey of vaccination practices in 36 state and federal correctional systems, representing over 75 percent of the prison population, only three of 36 respondents offered the hepatitis B vaccine to all inmates. Twenty-five (25) of 34 said they would do so if vaccines were supplied at no cost.

Integrating hepatitis A and hepatitis B vaccination into existing HIV, STD, and other services is not without challenges. These settings may lack personnel that are qualified to administer vaccine. Counseling and education staff may already be overburdened. In addition, educating clients about viral hepatitis is complicated (e.g., various types, complex disease progression, etc.) and some degree of screening may be necessary prior to vaccination. However, given the risk of infection for those who participate in high-risk behaviors, the gravity of the illness, and the cost of treatment, providing resources to organizations with ties to at-risk populations to carry out adult vaccination programs clearly appears to be a cost-effective response.

# THE ROLE OF STATE HEATH DEPARTMENTS

In December 2003, the National Viral Hepatitis Roundtable held its inaugural meeting to begin developing a national strategy for the elimination of viral hepatitis. The vaccination of at-risk adults will be a critical component. At the meeting, participants identified specific efforts that states should be, and many are, undertaking. These include:

- Working to ensure that HIV and STD programs train their staff on viral hepatitis;
- Training frontline counselors to incorporate HAV and HBV prevention messages into counseling sessions;
- Establishing referral networks and linkages to vaccine services in the community; and
- Capitalizing on resources from other public health programs to implement vaccine programs.

Some states dedicate their own funds to viral hepatitis prevention efforts. Others rely on creative solutions that help stretch resources. However, when activities are instituted with "one-time" funding or cobbled together with insufficient resources, sustainability can be an issue. Tenuous funding can prevent buy-in from necessary partners. It can also create high expectations that cannot be met. This can impact future collaborations.

An important part of the nation's response at the state level is the role of hepatitis C coordinators. The CDC's Division of Viral Hepatitis (DVH) provides 48 states, the District of Columbia, three cities and the Indian Health Service (IHS) funding for a hepatitis C coordinator position. Hepatitis C coordinators are charged with assisting state and local health departments in identifying public health and clinical activities in which viral hepatitis education, prevention and services (i.e., hepatitis C counseling and testing, hepatitis A and B vaccine) should be incorporated. Hepatitis C coordinators can play an important role in facilitating collaboration between state health departments and non-traditional sites.

# ROLE OF COMMUNITY-BASED ORGANIZATIONS (CBOs)

Why integrate viral hepatitis prevention with other programs? Many community-based organizations (CBOs) serve populations that are also at risk of viral hepatitis due to their various highrisk behaviors such as injection drug use or sex with multiple partners. Coordination would eliminate missed opportunities for prevention, which lead to ongoing transmission of viral hepatitis.

Getting more organizations involved in viral hepatitis prevention requires resources. Vaccines for Adults at Risk for Hepatitis (VFARH), a four-Center CDC initiative, has been collecting hepatitis A and hepatitis B vaccination data from 48 states and several cities and territories over the past few years. The data revealed that an estimated three million people are currently receiving services in public sector STD and HV prevention facilities, nationwide. Based on risk and susceptibility data, it is estimated that approximately 383,000 doses of hepatitis A vaccine and 3.75 million doses of hepatitis B vaccine would be needed to protect these people.

In addition, there are barriers to collaboration that do not relate to resources. Some CBOs may not be aware that the populations they serve are at risk of viral hepatitis. Even if they are aware, they may not know that vaccines are available for viral hepatitis or that they can play a role in disease prevention. Providers with expertise in viral hepatitis need to reach out to these potential partners and educate them about roles they can play.

In building relationships with other organizations within a community, it is important to determine appropriate collaborative roles. Not every organization serving at-risk adults needs to provide vaccination services. For some, referring their clients to another organization is the most appropriate course of action. Others will have the capacity to provide vaccination but will need technical assistance in implementing a program. Vaccination can be somewhat intimidating if an organization is not familiar with the process. Staff will require training and protocols will need to be modified. For example, the implementation of a vaccination program will require an additional level of paperwork for staff. This includes: informed consent forms, vaccine information statements (VIS), notations in medical chart, documentation of reasons for vaccine decline, appointment reminder card, and maintenance of immunization record.

Innovative approaches should also be considered. Personnel can be outsourced to organizations that do not have the staff capacity to provide vaccines, making vaccinations available to clients on a regular basis. Stationing mobile outreach vehicles at collaborating organizations has also proven effective.

Resources to facilitate the process of educating and tracking patients are available from the CDC and organizations like the Immunization Action Coalition. The Immunization Action Coalition has developed a step-by-step guide for organizations implementing adult immunization. The guide is available at: < http://www.immunize.org/guide/index.htm >.

## Role of Private Providers

Many at-risk adults do not seek services from CBOs. Instead, they receive their health care from private providers. These providers can play a vital role in the prevention of viral hepatitis. Unfortunately, all too often these providers are not aware of who should be vaccinated and even if they are, they do not perceive their patients to be "at-risk." Private providers need to be educated about conducting risks assessments and identifying when it is appropriate to vaccinate their patients that are at risk for viral hepatitis. These providers also need information on how to effectively educate their patients about viral hepatitis since patients may be unaware of the risk as well.

Unfortunately, in addition to the issues related to awareness mentioned above, there are also some disincentives for private providers when it comes to offering their patients vaccinations for viral hepatitis. Stocking vaccines requires that private providers cover the costs upfront. The vaccines must then be properly stored, which requires space and monitoring. For patients with private insurance that are vaccinated, a claim must be submitted, which the insurer may or may not reimburse. If the insurer does not pay, the private provider must obtain payment from the patient. To avoid the possibility of not being reimbursed, some private providers write a prescription for the vaccine, which the patient then fills. While this makes sure that the private

provider is not left "holding the bag" financially, it does create extra steps that only the most motivated of patients will take.

The American Medical Association has resources available for private providers on its web site. < http://www.ama-assn.org/ama/pub/article/2347-8586.html >.

#### **Vaccine Basics**

## Hepatitis A Vaccine

Date available: 1995

Dosage: Two doses, 6 to 18 months apart

Immunity: Protective antibody levels developed in 94% to 100% of adults 1 month after the first

dose. After the second dose, all persons have protective levels of antibody.

Private-Sector Cost per Dose: \$52 to \$62

Insurance Coverage: Many insurers offer coverage for at-risk populations. Coverage and reimbursements vary among insurers and individual insurance plans.

Guidelines: Prevention of hepatitis A through active or passive immunization: recommendations of the Advisory Committee on Immunization Practices (ACIP)

< http://www.cdc.gov/mmwr/preview/mmwrhtml/rr4812a1.htm >.

#### Hepatitis B Vaccine

Date available: 1981

Dosage: Three doses, over a 6-month period

Immunity: 1 dose, 30% to 50% protection; 2 doses, 50% to 75% protection; 3 doses, more than 90% protection. Note: some people, such as people living with HIV, may require more than three doses.

Private-Sector Cost per Dose: \$48 to \$59

Insurance Coverage: Many insurers offer coverage for at-risk populations. Coverage and reimbursements vary among insurers and individual insurance plans.

Guidelines: Hepatitis B virus, a comprehensive strategy for eliminating transmission in the United States through universal childhood vaccinations: recommendations of the Advisory Committee on Immunization Practices (ACIP)

< http://www.cdc.gov/mmwr/preview/mmwrhtml/00033405.htm >.

## Combined HAV/HBV Vaccine (Twinrix®)

Date available: 2001

Dosage: Three doses, over a 6-month period. Private-Sector Cost per Dose: \$77 per dose

Twinrix® is indicated for vaccination of persons 18 years of age or older.

With all viral hepatitis vaccines, there is a minimum amount of time needed between doses, but there is no maximum. Patients never need to restart the series.

## **Vaccine Financing**

health clinics (RHCs).

• Vaccines for Children In 1994, the federal Vaccines for Children (VFC) means-tested entitlement program began. The VFC program, funded by Medicaid and administered by CDC's National Immunization Program, provides free vaccine to VFC-eligible children. Eligible children include the uninsured, Medicaid recipients, Native Americans, or Alaska Natives at their doctors' offices. VFC also provides immunizations for children whose insurance does not cover immunizations at participating federally qualified health centers (FQHCs) and rural

#### 317

The "317" discretionary grant program is a federal immunization program that may be utilized to support adult vaccine purchase. 317 funds are used to support both activities at the CDC's National Immunization Program and grants to states, territories and selected metropolitan regions (total 64 grantees). 317 funds can be used to purchase vaccines for disadvantaged populations and to support immunization infrastructure, including professional education, outreach, surveillance of coverage levels and vaccine safety, and efforts to improve coverage rates in child and adult populations. Because there are no eligibility requirements for 317 funds, these funds may be used to support adult vaccine initiatives. Despite the VFC program, there remains a population of "underinsured" children who are not able to obtain vaccines without assistance and 317 funds can also be used to fill this gap. The 317 grant program does not require matching state funds.

Organizations receiving vaccine through VFC or 317 need to comply with specific accounting and administration rules and regulations. For example, organizations cannot charge for the actual dose of vaccine, although they can charge a dose administration fee. All patients receiving federally purchased vaccine must read a Vaccine Information Statement (VIS). The statements provide information on the vaccine, including possible side effects. VIS statements are available from the CDC.

## **State and Local Funding**

Some states also use their own funds to support vaccination. Half the states use state funds to purchase less than 10 percent of the vaccines provided to disadvantaged populations. Ten states use their own funds for more than 30 percent of such vaccines.

#### **About Vaccines**

## **History of Vaccination**

Attempts to vaccinate have been traced back to the sixth century. A little over 200 years ago, Edward Jenner developed the first vaccine by using cowpox to immunize against smallpox. Almost 100 years later, Louis Pasteur proved that protection against disease could be provided by the introduction of weakened germs that cause a relatively harmless infection. In 1885, Pasteur treated a boy that had been bitten by a rabid dog with a vaccine that prevented the development of rabies. Vaccine research continued during the remainder of the 19th century. It was discovered that in addition to using weakened viruses to make vaccines, they could also be made with dead viruses.

As with many scientific developments, vaccination was not without controversy. There were many in both the scientific community and the general public who vigorously opposed the deliberate introduction of deadly viruses into humans. These opponents organized in opposition to the new vaccines. However, by World War I, general vaccination had become routine.

#### **Misconceptions and Fears**

Most people recognize the benefits of vaccination. Nonetheless, there are those who question the safety and efficacy of various vaccines and are reluctant to get vaccinated. Some of the common misconceptions and fears that practitioners might encounter are listed below.

### I feel fine/I never get sick

If a person is not feeling sick, they may see vaccination as unnecessary.

## You may get the disease from the vaccine

The use of weakened or dead virus in vaccines has resulted in fears, by some, that you can actually get the disease that you are being vaccinated against from the vaccine.

### I don't like putting chemicals in my body

Some people prefer an alternative or homeopathic approach to health and view vaccines as harmful.

#### There are dangerous side effects

Serious reactions to vaccines are extremely rare. The risk of developing a disease as a result of failing to get vaccinated is far greater than the possibility of serious reaction to a vaccination. Some debates about the dangers of vaccination have received considerable media coverage. For example, in recent years there has been an ongoing debate on whether autism is related to childhood vaccination. There is no scientific evidence to support this link but the controversy has continued.

## You can still get the disease, even if you are vaccinated

No vaccine is 100 percent effective and not all vaccinated persons develop immunity. However, the vast majority of people who are vaccinated develop immunity.

In addition to the misconceptions and fears listed above, there are some religions that oppose vaccination, such as Christian Scientist and the Amish. Also, certain racial/ethnic populations may be weary of vaccines as a result of negative health-related experiences. For example, the legacy of the Tuskegee study has continued to have an impact on the views of many African Americans.

#### **Needle Fears**

Finally, don't underestimate the role the needle plays in some people's resistance to getting vaccinated. Fear of needles has been reported in studies as a reason people have declined vaccination. While this is not a significant factor in why people decline to be vaccinated, practitioners should be aware of it and be prepared to possibly spend a little more time explaining the benefits of vaccination to their patients that are "needlephobic."

#### Who Needs to be Educated

Various types of awareness efforts are required in order to support viral hepatitis prevention activities.

#### Non-Traditional Sites

Organizations providing services to at-risk adults need to learn about the role they can play in the prevention of viral hepatitis. Basic information must be provided in order to educate them, and they must receive training on the provision of viral hepatitis prevention services in order to develop their capacity.

#### Private providers

Since some at-risk adults receive their health services from private providers, these providers need to be educated about who is at risk so they can conduct risk assessments and offer vaccines or referrals as appropriate.

### At-Risk Populations

Health education and outreach activities need to target at-risk adults to inform them about the risks of viral hepatitis and the availability of vaccines. Studies indicate that when at-risk adults are educated about viral hepatitis they are receptive to vaccination. The importance of raising awareness cannot be underestimated. Some viral hepatitis vaccination initiatives at the local level have experienced limited success because not enough emphasis was place on raising awareness and educating the target population about the risks of viral hepatitis. As a result, many in the targeted populations went unvaccinated.

## **Screening Prior to Vaccination**

If someone has already been vaccinated against HAV and/or HBV or is already infected, then vaccination is unnecessary. Unfortunately, many people do not know if they are infected and it is fairly common for people to forget whether they have been vaccinated, especially when it comes to whether they completed the multi-shot series.

The cost effectiveness of screening can be determined by three factors:

- Cost of immunization;
- Cost of testing for prior infection; and
- Prevalence of infection within at-risk population.

However, there are other factors related to screening. Screening places additional demands on providers, who may already be struggling to implement a vaccination program. Additionally, for many of the populations targeted, there is a strong possibility that the client will not return for subsequent appointments, especially in some non-traditional settings. Given that even one shot of both hepatitis A and hepatitis B vaccines provides some immunity in most individuals, some providers argue that it should be provided without screening or that vaccination and screening should be conducted at the same time. If the screening indicates immunity or infection, there is no need for additional doses. Current guidelines support this approach. A drawback of not screening for HBV is that clients that are chronically infected with HBV will not learn of their status and be able to take steps to protect others from infection.

## **SECTION II: AT-RISK POPULATIONS**

Activities that specifically target adults that engage in high-risk behaviors have various advantages. These activities target people at greatest risk of infection and, as has been mentioned previously, venues already exist where hepatitis initiatives can be implemented. Activities targeting people at risk have proven to be effective, both in terms of disease prevention and cost.

When targeting adults that engage in high-risk behaviors, it is important to recognize that there are many sub-populations within these groups. For example, gay men/men who have sex with men (MSM) and injection drug users (IDUs) living in rural areas may require different outreach techniques than their urban counterparts. Multiple approaches may be necessary to address the diversity of at-risk populations.

To get an idea of what activities may already be underway in your community, check out Hepclinics.com. This web site provides a state-by-state listing of free or low-cost vaccination sites.

< http://www.hepclinics.com/templates/

1087834734906664639710/hepclinic/index.html?trycookie=1 >

## Why People Get Vaccinated

- Desire to be protected against infection
- Fear of infection
- Time and situation in which it was offered (convenience)
- Partner is getting vaccinated

## Why People Refuse Vaccination

- Health beliefs related to infection or vaccination
- Time constraints
- Worries about privacy
- Concerns about side effects
- "Just don't want it"
- Not aware of the risk
- Dislike of needles and pain
- Concerns about "mixing drugs" or refusal to put chemicals into the body
- Perceived low risk for infection
- Pregnancy or nursing
- Distrust of medical technology

## Gay Men and Men who have Sex with Men

Gay men and men who have sex with men are at elevated risk of becoming infected with HAV and HBV through sexual contact. The CDC's 2002 STD treatment guidelines call for comprehensive STD prevention services for MSM, including testing for HIV, syphilis, gonorrhea, and chlamydia at least annually, and vaccination against hepatitis A and B.

Ongoing gay men/MSM viral hepatitis education and vaccination programs have had some success. In 2000, 35.5 percent of MSM respondents in a survey conducted by the Gay and Lesbian Medical Association reported that they had received two doses of hepatitis A vaccine, compared with 22.3 percent reported in a similar survey in 1999. For hepatitis B vaccination, 38.9 percent reported receiving the three-dose series in 2000, compared to 33.4 percent in 1999. However, many health care providers and MSM remain unaware of the risks posed by HAV and HBV infection and the vaccination options available.

There are many opportunities at various venues to reach gay men/MSM and provide viral hepatitis services. The most successful approach to gay men/MSM vaccination is to identify, screen and vaccinate gay men/MSM as they access health care for other reasons: HIV testing, STD screening and treatment, or routine physical examinations. This type of integration of services, where the standard of care is vaccination of all at-risk adults, has proven successful in many venues, most notably, in primary care clinics serving the gay population.

Many gay men and MSM seek care from private physicians. Others go to health centers serving the gay community or HIV clinics. According to data from outbreak investigations and cross sectional surveys among MSM, 54 to 85 percent have a regular source of health care where prevention services could be provided. Unfortunately, a large percentage of gay men/MSM diagnosed with HAV or HBV accessed health care within 12 months prior to their infection, yet had not been vaccinated.

Stigma and homophobia can create challenges to reaching this population. With private providers and in

public-health settings, some gay men/MSM may not want to disclose their high-risk behaviors and providers may be uncomfortable taking a complete sexual history from their male patients, which would include asking the gender of sexual partners. MSM who do not identify themselves as gay or bisexual may be wary of accessing services at a gay-oriented community clinic. Private physicians whose practices include a large proportion of gay men appear to be better educated about vaccinating against viral hepatitis. These physicians may also be seeing a larger number of patients with hepatitis, which brings home the risk gay men and MSM face.

CBOs serving the gay community are important resources in reaching gay men/MSM. Many of these organizations have a long history of providing health and education services to gay men/MSM, including viral hepatitis education, outreach and vaccination. In addition to helping reach the target population, these organizations can also be valuable in educating private providers. For example, Callen-Lorde Clinic in New York City does targeted mailings to physicians to let them know that they can refer their gay men/MSM patients to the clinic for vaccination. This strategy serves both to educate providers about the need to talk to their gay men/MSM patients about viral hepatitis and also lets them know where clients can get vaccinated if the physician does not provide this service. Patients are more likely to follow through on a referral if they have the name of a provider instead of having to research vaccination sites.

Other programs take vaccination efforts out into the community. Gay Pride events, held across the country each year in June, are a very good way to reach large numbers of gay men. At the 2004 Gay Pride Festival in Kansas City, 243 men were vaccinated through a program supported by the Kansas City Department of Health. At New York City's Gay Pride Day Parade, riders on the Callen-Lorde Health Center's float handed out more than 30,000 stickers promoting vaccination. Callen-Lorde also had a booth at the Gav Pride Festival where stickers and brochures were distributed. Other outreach venues that have proven effective for reaching gay men/MSM include bars, gyms, bathhouses, and bookstores. Some organizations conduct awareness activities at these venues. Others provide a wider range of services such as HIV counseling and testing, STD screening, and vaccination for viral hepatitis. These services can be conducted onsite or via a mobile van.

For more information on reaching gay men/MSM go to:

GayHealth.Com
< http://www.gayhealth.com >
Gay and Lesbian Medical Association
< http://www.glma.org >
Immunization Action Coalition
< http://www.immunize.org >

The Gay and Lesbian Medical Association also has available patient education materials targeting gay men/MSM.

## CDC Launches National Effort to Prevent STDs in Gay Men/MSM

In spring 2004, CDC launched a national campaign to increase the immunization rate for vaccine-preventable hepatitis in gay men/MSM and other at-risk populations. The campaign was kicked off with a "Dear Colleague" letter from the Department of Health and Human Services urging all its partners at the federal, state, and local levels to promote and implement comprehensive interventions to prevent STDs among the gay men/MSM population, including immunization against vaccine-preventable hepatitis.

CDC has created a pocket information guide for vaccinating gay men/MSM and other at-risk populations against vaccine-preventable hepatitis and a wall poster with the same information, designed for clinical settings. In order to complement this program, the American Medical Association (AMA) has created a tri-fold pocket guide with information on appropriate coding of insurance claims related to immunizing at-risk populations against vaccine-preventable hepatitis.

For more information on CDC's initiative go to: < http://www.cdc.gov/ncidod/diseases/hepatitis/msm/index.htm >.

For more information on the AMA resources go to: < http://www.ama-assn.org/ama/pub/article/2347-8586.html >.

#### Incarcerated Individuals

Correctional facilities provide another opportunity to reach at-risk adults. People who are, or have been, incarcerated have high rates of both hepatitis A and B and hepatitis A and B outbreaks have been known to occur in correctional settings. Many people who are incarcerated have a history of high-risk behaviors.

One of the challenges in collaborating with correctional facilities is that they have a different mission, organizational structure and mindset from public health and community organizations. This does not mean collaboration is impossible. However, it may take longer to build a relationship, and the parties involved must recognize each others' priorities.

In addition, some people argue that correctional facilities may not be the best site to reach at-risk adults. Many of the adults coming into the system have already been exposed to hepatitis A and B, and therefore, do not need to be vaccinated. In addition, incarcerated individuals may spend less than six months in the facility, due to either release or transfer, which makes it difficult to complete the series.

In 2001, the Indiana State Legislature provided \$1.5 million in funding to the Department of Corrections to implement HIV, hepatitis C and syphilis screening for all incoming inmates. Offering hepatitis B vaccinations to incoming inmates for a one-year period was also included in the legislation. Screening for hepatitis B was not conducted.

The vaccination efforts had mixed results. There was a sense that vaccination in this population was not cost effective due to the high prevalence of hepatitis B exposure in the population. Providing screening would have been logistically difficult and an additional expense. Even with what is considered "a captive population," follow up was an issue due to transfer and release. Many inmates with sentences of less than six months were not offered the vaccine since subsequent doses could not be administered. Currently, vaccination is only offered to inmates that test positive for hepatitis C. The State used \$450,000 in carry over funds from these efforts to make vaccination available in STD clinics (see below).

## **Injection Drug Users**

Injection drug use is a highly effective means of transmitting hepatitis B and C and IDUs have higher than average rates of hepatitis A infection. Some studies have shown as many as 50 to 70 percent of IDUs become infected with HBV within 5 years of initially injecting drugs. Accordingly, IDUs have some of the highest prevalence rates of liver disease.

Stigma plays a significant role in efforts to reach IDUs. Many argue that this is a population that is exceedingly difficult to reach, will not take protective measures, and are often lost to follow up. However, studies indicate the opposite. When provided the opportunity to protect their health, whether it is through the adoption of safer injection techniques like the one-time use of sterile syringes or by getting vaccinated against hepatitis A and B, many prevention efforts targeting IDUs are successful. In studies, researchers have found various facilitators in getting IDUs vaccinated. These include: expedited appointments (being seen before other clients to minimize waiting time); free transportation to vaccination sites; incentives for each dose; flexible immunization schedules (higher vaccine doses and accelerated schedules); and one-stop shopping at service providers.

IDUs are reached in a variety of settings, including drug treatment programs, correctional facilities and STD clinics. However, one of the most effective sites for reaching IDUs are syringe exchange programs. Syringe exchange is one component of harm reduction, an approach that promotes alternatives to reduce the harm associated with a behavior. A key to harm reduction is providing services in a respectful, nonjudgmental manner.

While the main objective of most syringe exchange programs is to provide sterile syringes to IDUs, many have expanded their service over time to offer screening for viral hepatitis and other STDs, vaccination for hepatitis A and B, information on safer injection techniques, overdose prevention, and referral to other services such as health care, housing, drug treatment, and legal aid. The expansion of services depends heavily on the availability of resources.

The Chicago Recovery Alliance (CRA) provides a range of services throughout the city using large vans as mobile outreach sites. Over the last five years, hepatitis A and B vaccines have been available to clients. The vaccine is provided by the health department so CRA can offer the vaccinations free of charge. The entire outreach staff has been trained to provide vaccinations. Since they have been available, over 2,500 clients have been vaccinated. The completion rate for the three-dose series is 84 percent, which is much higher than the completion rates achieved in most other non-traditional vaccination settings. CRA believes that this level of success has been achieved because of their respectful and long-term connection with their clients.

Syringe exchange programs tend to build a strong rapport with clients. While clients may initially come in only to exchange syringes, over time trust develops and clients take advantage of the other services offered such as HIV counseling and testing or referral to drug treatment.

CRA stresses educating clients about multiple ways to reduce their risk, whether through the adoption of safer injection techniques, the use of sterile injection equipment in addition to syringes (provided by CRA) or by practicing safer sex (CRA provides condoms and lubricant). "Since the clients trust us, they also tend to trust what we tell them," states Dan Bigg of CRA. "One reason why many of our clients get vaccinated is that we have a long-time relationship with them."

Recently, the local health department had a supply of vaccine available that was due to expire. CRA contacted methadone treatment programs to arrange onsite vaccination for clients. While over 300 people were vaccinated, according to Bigg there was a significant difference between working with the clients at the methadone sites and working with CRA's own clients.

"At the methadone sites, the clients didn't know who we were and they had generally not been educated about the risks of viral hepatitis," states Bigg. "The completion rate for the whole series was about 40 percent, which is still good, but in our experience it is more effective to integrate viral hepatitis education and vaccination into a program on an ongoing basis."

"Ideally, the best people to conduct vaccination efforts are those working within the program who have earned the trust of clients and have the opportunity over time to offer and complete the vaccination series," adds Bigg. Learn more about CRA's services for IDUs at: < http://www.anypositivechange.org/menu.html >.

#### Homeless

Homeless people are confronted by many challenges, including high rates of mental illness, substance abuse and HIV. Services targeting homeless people, including health care for the homeless services, provide an opportunity to reach this population. In addition, homeless people can be reached through services that address their other needs, such as drug and alcohol treatment providers, HIV/STD clinics, and mental health services. Because of their homeless status, this population is at increased risk of being lost to follow up so any contact they have with providers should be viewed as an opportunity to initiate vaccination.

## **Sexually Transmitted Disease (STD) Clinics**

People seeking treatment in STD clinics have obviously engaged in behaviors that would also put them at risk of HAV and HBV. Since these individuals are seeking treatment in a clinic, they may not have access to any other health care providers. The clinic visit may be a rare opportunity to offer viral hepatitis services.

Studies indicate that vaccination acceptance rates in STD-related settings vary significantly, from 23 to 69 percent. Variables include how it was offered (integrated into the treatment encounter as opposed to being offered by the researchers) and the setting (onsite or through referral).

The studies indicate that onsite vaccination is particularly effective. Even when studies offered incentives or provided transportation, many patients did not follow through on referrals when it entailed going to a different site. Health department clinics that have created linkages between their STD and immunization programs have found that some clients do not follow through on a referral that involves going to a different room in the health department's facility—they just walk out the door. Clearly, strategies are necessary to, 1) educate about

the importance of vaccination so that patients recognize the benefits of vaccination and are sufficiently motivated to follow through on referrals; and 2) facilitate the referral process.

The need to develop effective referral strategies can be avoided by integrating vaccination into STD treatment protocols. The Indiana State Department of Health makes vaccines available to STD service providers using carry over funds from a program that provided vaccines in correctional settings. The funds, totaling \$450,000, should last about two years.

Initially, the health department made vaccine available to any county offering STD services. Currently, 13 providers are participating. The providers request the vaccine from the health department, which then orders the vaccine. The vaccine is shipped directly to providers.

According to Cheryl Pearcy, Hepatitis C Coordinator, almost all the providers were very receptive to integrating the vaccines into their services. Pearcy had already been working with the providers to integrate hepatitis C screening into their services. "I built on these previous efforts and it really seemed to help that there was an awareness about hepatitis-related issues," she reports. The health department did have to provide some information about vaccination to the clinics. In addition, some materials, such as order forms for vaccine, had to be developed.

The STD service providers do not screen for prior exposure to hepatitis A and B. Logistically, the screenings are not possible, nor are they cost effective. Currently, the state lab does not have the capacity to conduct screening for hepatitis A and B. If the screenings were conducted, there would be a very long turn around time, in which the client could be lost to follow up. When clinics have conducted screenings, they have found that there is very little immunity in the client population.

Since many young people seek services from STD clinics, it is important to have policies in place addressing whether they can be vaccinated. Most states have laws that allow minors to consent to STD services. However, whether vaccination is considered an "STD service" can be interpreted differently. Programs should be sure to determine if minors require parental consent. In Indiana's case, the determination was made that vaccination was STD treatment, opening the door to use VFC funds to cover the costs. This issue was a major concern to the largest STD service provider in the state, which was reluctant

to take part in the vaccination program until it was resolved.

A manual on integrating vaccination into STD services, developed by the Health and Human Services Agency of San Diego County is available at: < http://www.cdc.gov/ncidod/diseases/hepatitis/training/index.htm >.

#### HIV

The CDC estimates that between 850,000 and 950,000 people are living with HIV (PLWH) in the United States. HIV services provide access to people at risk and an opportunity to ensure that people with HIV get the viral hepatitis-related services they need.

HBV rates among PLWH are much higher than those in the general population and vaccination levels are low. People with HIV should be vaccinated against HAV and HBV, since infection can create serious health complications. Although these vaccines are safe for persons who are immunocompromised, the response rate may not be strong enough to provide protection and response to the vaccines tends to decrease as HIV disease progresses. Booster doses of HBV vaccines may be necessary.

According to the 2004 National ADAP Monitoring Report, 22 AIDS Drug Assistance Programs (ADAPs) cover hepatitis A and B vaccine. However, state ADAP programs are facing significant funding shortages so whether additional states will add coverage is unknown.

The National ADAP Monitoring Report is available online at: http://www.nastad.org/pub\_careandtreatment.asp? publication\_category\_id=1&publication\_subcategory\_id=6.

## SECTION III: LESSONS FROM THE FIELD

## New York State: Closing the Gap on Adults at Risk for Hepatitis A and B

Immunization, HIV and STD are working together to improve the health of adults at risk for viral hepatitis

In New York State (NYS), adults at risk of hepatitis A and hepatitis B virus infections have access to free hepatitis vaccines through county health department programs. The widespread availability of vaccines for adults is the result of years of collaboration between the New York State Department of Health's (NYSDOH) Immunization, STD Control and HIV Prevention programs. The three programs' commitment to integrating services to reach at-risk adults has enabled NYS to begin closing the gap on adults at risk of hepatitis A and hepatitis B virus infections who remain unvaccinated.

The Adult Hepatitis Vaccination Program began in 1995, when there was a strong focus nationally on immunizing infants, children and adolescents against the hepatitis B virus. The federally funded Vaccines for Children program, which provides free vaccine to eligible children under the age 19 in the United States, was in its infancy, and hepatitis B vaccine school entry requirements were on the docket in many state Legislatures in an effort to capture children and adolescents who were not yet immunized. With a strong national and state focus on infants and children, the NYSDOH Immunization Program was concerned that they not lose sight of at-risk adults who were unvaccinated and susceptible to hepatitis B. (Hepatitis A vaccine was licensed in 1995, but not yet widely available.)

To address these concerns, the Immunization Program allocated state funds to support adult hepatitis B vaccination, and worked with the STD Control Program to implement the vaccine program within county STD clinics. Together, the two programs reached out to the county health departments in the 57¹ upstate counties by letter to inform them of the availability of hepatitis B vaccine. However, the counties were slow to enroll in the program and by 2000, only about 15 counties were enrolled. NYSDOH Hepatitis B Coordinator, Elizabeth Herlihy, explains that the Immunization Program was cautious about encouraging the remaining counties to participate in the program due to the uncertainty of continued vaccine funding for adults at the time.

<sup>&</sup>lt;sup>1</sup> There are fifty-seven counties that fall under the NYSDOH's jurisdiction. The New York City Department of Health and Mental Hygiene (NYCDOHMH) is responsible for serving the five boroughs of New York City.

During 2001, the NYSDOH's Immunization Program renewed its commitment to adults by expanding the Adult Hepatitis Vaccination Program. This policy decision, Herlihy notes, was consistent with the strong integration messages that hepatitis B coordinators and immunization programs were hearing from CDC at this time. Across the country, at meetings and conferences, coordinators were urged to work with other public health programs (e.g., STD, HIV) to integrate hepatitis activities, including vaccination, into programs already serving adults and adolescents at risk for hepatitis.

The Immunization Program and the STD Control Program again sent a letter to all of the 57 upstate counties encouraging them to join the Adult Hepatitis Vaccination Program, if not already enrolled. As they learned from previous experience, having vaccine available at no cost does not guarantee that all the county health departments will quickly sign up for the program. County health departments are often overwhelmed with day-to-day issues and have little capacity for new initiatives. In addition, targeting at-risk adult populations is often a formidable task. Herlihy, along with regional DOH staff, actively pursued the counties' participation in the program by telephoning, sending follow up letters, and visiting the counties. To date, hepatitis A, hepatitis B and Twinrix® vaccines are being provided at no cost to at-risk adults in 55 of the 57 upstate New York counties, with the remaining two counties poised to join the program this year.

While the Adult Hepatitis Vaccination Program was expanding to STD clinics, the NYSDOH's Immunization Program continued to search for other ways to increase vaccination efforts targeted to at-risk adults and adolescents. In 2002, the NYSDOH AIDS Institute Division of HIV Prevention provided a letter and resource packet to HIV prevention providers explaining the updated STD Treatment Guidelines, which recommended annual STD screenings, HIV testing and hepatitis A and B vaccination for sexually active men who have sex with men. With these recommendations in mind, Herlihy and Susan Klein, Director of the Division of HIV Prevention at the AIDS Institute, began to meet together to discuss how to expand access to vaccine to individuals receiving HIV/AIDS services. In NYS, licensed health care personnel (e.g., physicians, registered nurses, physician assistants) are required to administer vaccine. Because many HIV prevention providers do not have staff who meet these

requirements, HIV providers would likely refer their clients to the public health programs for access to free vaccine.

At this time, several of the county immunization programs, on their own initiative and supported by the NYSDOH, were already successfully working with HIV providers by serving as a referral source for their clients or by providing vaccine onsite at CBOs. Klein and Herlihy decided to formalize the policy encouraging collaboration by sending letters to the county health department immunization programs and to state-funded HIV prevention providers, informing the HIV prevention providers of the availability of free vaccine through county health department programs, and encouraging them to call the local health department for information on how to refer individuals. Karen Schlanger, the New York City Department of Health and Mental Hygiene's (NYCDOHMH) Hepatitis Program Director, also collaborated on the letter and provided information on where to access free vaccine in NYC. The letter (see pages 255–258) offers clear steps on how to integrate hepatitis education and information into HIV programs and services, and provides information on where to get free materials and information on viral hepatitis in NYS.

The letter was sent to HIV prevention providers in August 2003, and Klein reports that the response has been overwhelmingly positive. As Klein notes, "the HIV programs are eager to do anything that they can to help advance the health and well being of the people that they work with in the communities." The NYS HIV Prevention Planning Group was supportive and encouraged the project to move forward. The NYS Immunization Program, the NYS AIDS Institute and the NYS STD Control Program, however, view the letter as just one of the first steps in an effort that will have to be sustained over time. Ensuring that adults at risk are able to access vaccine requires not only encouraging providers to participate in the program, but also improving hepatitis education and awareness so that both clients and providers understand the risks for hepatitis infections. Further, the NYSDOH must be able to provide the resources, training and technical assistance that is needed by the counties to implement a successful vaccine program.

Several efforts within the NYSDOH will likely strengthen the Adult Hepatitis Vaccination Program. In the past year, Herlihy and Klein developed an interdepartmental work group on hepatitis A and B that includes the NYSDOH STD, HIV and Immunization programs as well as the state Office on Alcoholism and Drug Abuse Services and the Department of Correctional Services. Work group members strategize on how to collaborate to address hepatitis A and B across the state, look for ways



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Antonia C. Novello, M.D., M.P.H., Dr.P.H. Commissioner Dennis P. Whalen Executive Deputy Commissioner

August 2003

#### Dear HIV Prevention Provider:

We are writing to share information about resources for helping to make sure that persons at risk for hepatitis A and B are aware of their risk and know that vaccines to prevent hepatitis A and B infection are available. Due to shared modes of transmission and populations at risk, hepatitis A, B and C are common among persons at risk for or living with HIV. Chronic hepatitis C, along with chronic and acute hepatitis B may be life-threatening and they are the leading cause of chronic liver disease. Hepatitis A can also have serious consequences, especially for people living with hepatitis C. Hepatitis A and B can be prevented through vaccination. Currently there is not a vaccination for hepatitis C, however, the CDC recommends that individuals chronically infected with hepatitis C be vaccinated against hepatitis A and those with risk factors should be vaccinated against Hepatitis B to prevent further liver damage.

Individuals at high risk for hepatitis A for whom vaccination is recommended include men who have sex with men (MSM) and injection drug users (IDUs). Hepatitis B vaccine is recommended for MSM, IDUs, persons who are HIV-infected, sex contacts of persons who are infected with hepatitis B, and those who have multiple sex partners. The CDC recommends that all MSM get vaccinated against both hepatitis A and B. Despite safe and effective vaccines against hepatitis A and B, studies have shown that vaccination rates are low among MSM. Men infected with both chronic hepatitis B and HIV have been found to have extremely high liver-related mortality rates

Availability of Vaccine for Hepatitis A and/or B Vaccination for hepatitis A and/or B is available at many doctors' offices, health care clinics and STD clinics. Often, an individual's health insurance covers costs associated with hepatitis A and B screening and vaccination for high-risk adults. Persons enrolled in the Medicaid or the AIDS Drug Assistance Program (ADAP) are covered for both the antigen screening tests, and the hepatitis A and B vaccines are part of comprehensive primary care visits.

The NYS Department of Health Immunization Program provides free hepatitis A, B, and Twinrix (combination hepatitis A&B) vaccine to local health departments in most upstate counties. The vaccine is targeted for high risk adults and adolescents seeking services through the local health department, including STD clinics and HIV counseling and testing programs. In areas of the state outside of New York City (NYC), call your local health department for information about how to refer individuals at risk for free vaccination.

In NYC, the NYC Department of Health and Mental Hygiene (NYCDOHMH) makes free vaccine available at certain STD clinics. These sites are identified on the attached listing. Hepatitis B vaccine is available to anyone. Hepatitis A vaccine is limited to MSM, IDU and persons living with HIV and/or liver disease. The NYCDOHMH also distributes hepatitis vaccine to some HIV prevention programs. To explore access to vaccine for your organization, you can call Dr. Stephen Friedman at 212-676-2256 or Dr. Jane Zucker at 212-676-2248.

We encourage you to reach out to the NYCDOHMH or to your local health department, to obtain specific information about how individuals can access free vaccine.

*Free Materials and Training About Hepatitis A and B* Attached are reference sheets that highlight how to access free materials and training about hepatitis A and B and access to free vaccine within NYC.

Action Steps It is important for MSM, IDUs, individuals with HIV, individuals with hepatitis C, and other persons at high risk for hepatitis A and B to be aware of their risk and to be informed of the availability of antigen screening and vaccine against Hepatitis A and B. Please consider ways in which you can incorporate information about hepatitis A and B into your programs and services. For example:

- Offer clients clear information about how to avoid exposure to viral hepatitis as part of prevention counseling.
- Incorporate information about hepatitis A and B into their risk reduction presentations, especially in/at venues where high risk populations gather;
- Make brochures and information about hepatitis A and B available to clients;
- Educate active IDUs and MSM about vaccination;
- Refer active IDUs to syringe exchange programs and/or ESAP pharmacies for clean injection equipment;
- Provide information about free vaccine available from local health departments;
- Provide HIV-infected individuals and their partners information about hepatitis A and B and referrals, where appropriate, as part of case management; and
- Use materials about hepatitis A and B as part of a discussion on maintaining health behaviors in MSM support groups and support groups for HIV-infected individuals.

We appreciate your assistance in informing individuals about hepatitis A and B, helping them assess their risk(s) and aiding them in accessing vaccine.

Sincerely,

Susan J. Klein, M.S.

Director, Division of HIV Prevention

AIDS Institute

Elizabeth J. Herlihy, R.N., M.S.

Hepatitis B Coordinator Immunization Program

## Additional Resources: Materials and Training Related to Hepatitis A and B

Free Materials About Hepatitis A and B A variety of print materials about hepatitis A and B are available in camera ready format and copyright free from the Immunization Action Coalition. The Immunization Action Coalition maintains a web site at: www.immunize.org. Materials suitable for use with adults who may be at risk include the following items:

Item#	Title
P4035	ImmunizationsNot Just Kids' Stuff
P4041	Shots for Adults with HIV
P4080	Hepatitis A is a Serious Liver Disease: Should you be Vaccinated?
P4112	Every Week Thousands of Sexually Active People Are Infected with Hepatitis B:
	Get Protected! Get Vaccinated!
P4115	Hepatitis B: 100 Times Easier to Catch than HIV!
P4116	You Don't Have to go All the Way to Get Hepatitis A: Get Vaccinated!

The Gay and Lesbian Medical Association provides information about hepatitis A and B, as well as resources for creating a safe clinical environment for LGBT clients at: www.glma.org.

The NYS Department of Health Immunization Program recently established a Viral Hepatitis Web Site. To access it, visit: http://www.health.state.ny.us/nysdoh/hepatitis/en/index.htm

The NYS Department of Health AIDS Institute offers a brochure, "Diseases that Can Be Spread During Sex" (publication 3805), that highlights risks, symptoms and recommendations for hepatitis B vaccination. This brochure is available in English and Spanish can be obtained through the HIV/AIDS Consumer Educational Materials Order Form, available by calling 581/474-9866 or by e-mail directed to: hivpubs@health.state.ny.us. AIDS Institute "Questions and Answers" on viral hepatitis and HIV can be found on the web at:

http://www.hivguidelines.org/public\_html/center/clinical-education/clinical-education.shtml

The Centers for Disease Control and Prevention offers fact sheets for hepatitis A and B on-line at:

http://www.cdc.gov/ncidod/diseases/hepatitis/a/fact.htm http://www.cdc.gov/ncidod/diseases/hepatitis/b/fact.htm

Training for Staff The AIDS Institute offers a free, half-day training entitled "The ABC's of Hepatitis and HIV". To view the Statewide Calendar of HIV/AIDS Trainings on the Internet go to: http://www.health.state.ny.us/nysdoh/aids/training.htm.

## Hepatitis A and B Vaccine, Materials and Training Available Through the New York City Department of Health and Mental Hyglene

*Free hepatitis A and B vaccine:* Free hepatitis A and B vaccine is available at the three NYC DOHMH STD Clinics listed below. Hepatitis B vaccine is available to anyone. Hepatitis A vaccine is limited to men who have sex with men, people who inject drugs, and people with HIV and/or liver disease.

Riverside STD Clinic 160 West 100th St., 1st Floor Manhattan (212) 865-1951

Morrisania STD Clinic 1309 Fulton Ave., 2nd Floor Bronx (718) 901-6564

Crown Heights STD Clinic 1218 Prospect Place, 2nd Floor Brooklyn (718) 735 0580

Gay men/men who have sex with men can also get hepatitis A vaccine at the Chelsea STD clinic and hepatitis B vaccine from the Chelsea immunization clinic, open Monday and Friday. The Chelsea STD clinic is located at 303 9th Avenue, 2nd Floor (at W. 28th St.). Call (212) 239-1718 for details.

*Free Promotional Materials:* Free fact cards that list NYC DOHMH STD clinics where hepatitis A and B vaccination and hepatitis C testing are offered and provide basic information on hepatitis A, B and C can be ordered by calling (212) 427-5120.

*Training for Staff:* The HIV Training Institute offers a free full-day training entitled "Hepatitis C: A Training for Service Providers". Call (212) 341-9810 or e-mail: losborne@health.nyc.gov to obtain a schedule or to register.

For Further Information About Hepatitis C in New York City: Please contact:

Karen Schlanger, M.P.H. Director, Hepatitis C Program NYC Department of Health and Mental Hygiene 125 Worth Street, CN-22, Room 326; New York NY 10013. Telephone: (212) 227-6021 to develop policies that support hepatitis integration within each of their programs, and educate their constituencies in the counties of hepatitis A and B resources, including vaccine availability.

The NYSDOH Bureau of STD Control Program, for example, has taken a leading role in educating its providers about viral hepatitis and the availability of free vaccine. Over the past nine months the STD Control Program held a series of "STD Clinician Training Programs" throughout upstate New York. These trainings were targeted towards physicians, nurse practitioners, nurses and other providers working in HIV and STD. Information on viral hepatitis was incorporated into three of the presentations given at the training, and the informational packets given to participants included the "Dear HIV Prevention Provider" letter written by Klein and Herlihy and a hepatitis C informational letter written by Marilyn A. Kacica, MD, Medical Director of the NYSDOH Regional Epidemiology Program.

Another ongoing collaboration, soon to come to fruition, is the development of the NYS Viral Hepatitis Strategic Plan. A core group of representatives from several of the Programs, Centers and Divisions at NYSDOH led the writing of the plan, and approximately 65 stakeholder groups from across NYS, including the NYCDOHMH, were involved and provided input into the plan. The plan covers five years and has four major components: Prevention, Education, Surveillance and Research, and Medical and Case Management.

This year, the NYS Immunization Program is incorporating language into its contracts with the counties requesting that they assess hepatitis immunization needs within their community and provide hepatitis vaccines to at-risk adults through participation in the Adult Hepatitis Vaccination Program. Other current initiatives by the Immunization Program include a hepatitis vaccine pilot project with 11 county jails and a survey of all 57 upstate counties to assess their involvement in health services provided at their county jails. The purpose of this study is to assess feasibility of local health departments providing hepatitis vaccination services at their county jails.

As the NYS experience shows, having hepatitis A and B vaccine available for adults is only one component needed in an adult hepatitis vaccination program. Getting busy

county health departments, STD clinics and HIV programs to provide vaccine or referrals to vaccine requires considerable communication, follow-up, education and resources. The leadership, commitment, supportive policies and prioritization of funds demonstrated by the NYSDOH Immunization, HIV Prevention and STD Control programs were all critically important to the success of the Adult Hepatitis Vaccination Program. With all of this in place, NYSDOH is now well positioned to close the gap on adults at risk of hepatitis A and B virus infections through the provision of hepatitis vaccines.

For more information please contact:
Elizabeth J. Herlihy, RN, BSN, MS
Hepatitis B Coordinator & VPD Surveillance Officer
New York State Department of Health
Immunization Program
Corning Tower, Room 649
Empire State Plaza
Albany, NY 12237

Phone:(518) 473-4437 Fax: (518) 474-1495

EJH04@health.state.ny.us

#### **Lessons Learned**

- Convincing providers to participate may require multiple requests and ongoing education to increase their awareness about viral hepatitis and the role they can play in prevention efforts.
- Provide clear directions and a step-by-step process on how providers can participate in prevention efforts.
- Some providers will need resources, training and technical assistance to implement successful vaccination programs.
- A work group can focus key stakeholders on the issue, allowing members to strategize on how to collaborate, develop policies that support hepatitis integration, and educate their constituencies.
- A strategic plan can provide a clear road map that facilitates buy in and sustaining of programs.
- Needs assessment can help identify populations in need of vaccination services.
- Outreach and education efforts also need to target at-risk adults so they are aware of the risk they face and are motivated to get vaccinated.
- During program integration, clinicians (physicians, nurse practitioners and nurses) require training on viral hepatitis and vaccination so they can effectively educate clients. Awareness efforts should not just focus on stakeholders and administrators.

## Sources

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< http://www.cdc.gov/nip/publications/6mishome.htm >. Accessed June 15, 2004.

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Institute of Medicine. *Calling the Shots: Immunization Finance Policies and Practice* Washington, DC: Institute of Medicine, 2000.

Kahn J. Preventing Hepatitis A and Hepatitis B Virus Infections among Men who have Sex with Men. *Clinical Infectious Diseases* (35):1382-7, 2002.

Lum PJ, Ochoa KC, Hahn JA, Shafer KP, Evans JL, Moss AR. Hepatitis B Virus Immunization Among Young Injection Drug Users in San Francisco, CA: The UFO Study. *American Journal of Public Health* (93): 919-923. 2003.

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Rich JD, Ching CG, Lally, MA, Gaitanis, MM, Schwarzapfel B, Charuvastra A, Beckwith CG, Flanigan TP. A Review of the Case for Hepatitis B Vaccination of High-Risk Adults. *American Journal of Medicine* (114):316-318. 2003.

## Appendix A: The HIV-Viral Hepatitis Connection

## **ABBREVIATIONS**

**AIDS** Acquired

Immunodeficiency Syndrome

**HAV** Hepatitis A Virus

**HBV** Hepatitis B Virus

**HCV** Hepatitis C Virus

**HIV** Human

**Immunodeficiency** 

Virus

IDU Injecting Drug

Use/User

MSM Men who have sex

with Men

STD Sexually Transmitted

Diseases

Following is a select annotated bibliography of the public health literature regarding the connection between infection with HIV and with viral hepatitis.

The articles herein were identified either through a search of articles in major journals with textwords "HIV" and "Hepatitis" in the MedLine and/or PsychInfo database from the period 1994-2000, or through a review of sources NASTAD utilizes. Articles were selected for inclusion based upon their relevance for public health efforts against viral hepatitis within the context of HIV programs. Note that due to delays in indexing, some relevant articles may not be included. Articles are organized under the following 3 subject headings: Care and Treatment, Epidemiology and Prevention.

Readers who are aware of important articles not included in this review are encouraged to send copies to NASTAD's Viral Hepatitis Program at the following address: <a href="lschowalter@nastad.org">lschowalter@nastad.org</a>.

## **CARE & TREATMENT**

Bessensen, Mary; Ives, David; Condreay, Lynn; et al. (1999) Chronic Active Hepatitis B Exacerbations in Human Immunodeficiency Virus-Infected Patients Following Development of Resistance to or Withdrawal of Lamivudine. Clinical Infectious Diseases, Vol. 28, 1032-1035.

Some HIV-HBV coinfected patients taking lamivudine (a nucleoside analog reverse transcriptase inhibitor used against both viruses) experienced hepatic flares after discontinuing the drug and changing to a different regimen.

Buffington, Joanna; Rowel, Randy; Hinman, Johanna M.; Sharp, Katherine; Choi, Simon. (2001) Lack of Awareness of Hepatitis C Risk Among Persons Who Received Blood Transfusions Before 1990. American Journal of Public Health, Vol. 91, No. 1, pp. 47-48.

The Integration of Viral Hepatitis into HIV/AIDS Programs:

Nine focus groups conducted in the United States with individuals who received blood transfusions prior to 1990 identified an overall lack of awareness of HCV and a lack of perception of risk. Targeted campaigns are needed to increase awareness among individuals who received transfusions prior to 1992.

Crawford, Anne M. (1996) **Stigma associated with AIDS: A Meta-Analysis.** Journal of Applied Social Psychology, Vol. 26, No. 5, pp. 398-416.

This meta-analysis of 21 studies compared the stigma associated with AIDS with that associated with other stigmatized conditions, including hepatitis. The meta-analysis found that "there is a somewhat greater degree of stigma associated with AIDS." However, it is worth noting that the articles included only the period 1980-1992.

Davis, Gary L.; Balart, Luis A.; Schiff, Eugene R.; et al. (1994) Assessing Health-Related Quality of Life in Chronic Hepatitis C Using the Sickness Impact Profile. Clinical Therapeutics, Vol. 16, No. 2, pp. 334-343.

The Sickness Impact Profile was used to identify the impact of both chronic hepatitis C and treaments with alfa interferon. Pre-treatment, patients scored significantly worse than a control group of the general population, but demonstrated significant improvement in work, sleep and rest, and recreation and pastimes scores post-treatment.

Davis, Hillel; Kaplan De-Neour, Atara; Shouval, Daniel; et al. (1998) **Psychological Distress in Patients with Chronic, Nonalcoholic, Uncomplicated Liver Disease**. Journal of Psychosomatic Research, Vol. 44, No. 5, pp. 547-554.

Even asymptomatic liver disease can lead to significant psychological distress. In a study of 80 subjects with minimal hepatitis or cirrhosis, 64 had minimal or no physical symptoms yet 50% reported distress, which was severe for 15%. Mental health diagnoses were possible among 45% of the asymptomatic individuals. These findings were attributed to concern about the disease and/or to possible subtle changes in central nervous system functioning.

Deinstag, Jules L.; Schiff, Eugene R.; Mitchell, Mark (1999) Extended Lamivudine Retreatment for Chronic Hepatitis B: Maintenance of Viral Suppression After Discontinuation of Therapy. Hepatology, Vol. 30, No. 4, pp. 1082-1087.

Sustained use of lamividine, an antiretroviral medication used to treat both HIV and HBV, is able to eliminate HBV, and it may be possible to discontinue therapy after confirmed loss of hepatitis B antigens or antibodies.

Del Pozo, M.A.; Arias, J.R.; Pinilla, J. et al. (1998) Interferon Alpha Treatment of Chronic Hepatitis C in HIV-Infected Patients Receiving Zidovudine: Efficacy, Tolerance and Response Related Factors. Hepato-Gastroenterology, Vol. 45, pp. 1695-1701.

Recombinant interferon alpha therapy is reported to be an effective therapy, particularly with active chronic HCV patients who are HIV-positive, on zidovudine, and have CD4+ cell counts below 200.

Edlin, Brian R.; Seal, Karen H.; Lorvick, Jennifer; Kral, Alex H.; Ciccarone, Daniel H.; Moore, Lisa D.; Lo, Bernard. (2001) Is It Justifiable To Withhold Treatment For Hepatitis C From Injection Drug Users? New England Journal of Medicine, Vol. 345, No. 3, pp. 211-214.

This article challenges the 1997 National Institutes of Health consensus statement on the management of hepatitis C that recommends that persons who use illicit drugs not be offered treatment for hepatitis C infection until they had abstained from use for at least six months. The authors consider four possible arguments for withholding treatment of HCV infection from drug users: poor adherence to treatment regimens, side effects of treatment, the risk of re-infection with HCV, and the lack of urgency regarding the initiation of treatment for HCV infection. The authors demonstrate that there is little evidence to support the arguments against treatment, and propose an alternative policy based on individualized risk.

Heddle, Nancy; Kelton, John G.; Smaill, Fiona; et al. (1997) **A** Canadian hospital-based HIV/hepatitis C look-back notification program. Canadian Medical Association, Vol. 157, No. 2, pp. 149-154.

Pediatric patients in Canada who received blood transfusions before the start of routine screening for HIV (1985) and HCV (1990) were notified through a look back program. Of 1024 (of 1546) patients successfully reached with a questionnaire, 493 responded. Most had not subsequently been tested for HIV or HCV but indicated that that they would be as a result of the letter, supporting the use of notification programs.

Joseph, A.T.; Chandraman, S.; Cox M. (2000) The need to exercise caution in the management of patients co-infected with HIV and hepatitis B (letter). International Journal of STD & AIDS, Vol. 11, pp. 131-132.

In a case study of a patient co-infected with HIV and HBV, Joseph, Chandramani, and Cox (2000) reported that the patient died after treatment with HAART. "Even though the cause for his deterioration is unclear, it is possible that the liver damage could have been more severe than initially thought, subsequently aggravated by drug therapy. This case illustrates

The Integration of Viral Hepatitis into HIV/AIDS Programs:

the need to exercise caution when co-infected patients are considered for treatment, especially those with mildly decompensated cirrhosis and the need to include liver histology in the evaluation process."

Klaus, Barbara D.; Grodesky, Michael J. (1998) **Implications of HIV and Hepatitis C Coinfection.** The Nurse Practitioner, Vol. 23, No. 12, pp. 78-81.

A review of the issues relating to HIV-HCV coinfection from the perspective of the nursing profession. "Clinicians caring for patients with both HIV and HCV infection should consider referring these patients to experienced hepatologists for treatment option evaluation."

Owens, D.K.; Cardinalli, A.B.; Nease, Jr., R.F. (1997) **Physicians'** assessments of the utility of health states associated with Human Immunodeficiency Virus (HIV) and Hepatitis B (HBV) infection. Quality of Life Research, Vol. 6, pp. 77-85.

In an survey, 200 house staff and physicians ranked the impact of HIV and HBV on quality of life (QoL) with a ranking system in which 0=death and 1=good health. The respondents provided scores of 0.833 for asymptomatic HIV and 0.917 for asymptomatic HBV, recognizing that both diseases have an impact on QoL even before the onset of symptoms. Symptomatic HIV was scored at 0.417 and mildly symptomatic HBV at 0.667, indicating significant impairment by both conditions. AIDS (i.e., late stage HIV disease) and severely symptomatic HBV (i.e., cirrhotic complications of liver disease) were provided identical scores of 0.167, indicating a QoL in the lowest quartile. Overall, even HBV with only moderate symptoms was scored lower on the QoL scale than almost all other non-HIV conditions, including moderate stroke, monocular blindness, and severe angina. The authors indicate that their findings should be incorporated into the policymaking process: "Cost-effectiveness studies of HIV interventions should account for the effect of the intervention on both mortality and morbidity, particularly when the morbidity of the condition is severe." (Owens, Cardinalli, and Nease 1997)

Renaud, Anne; Ryan, Bill; Cloutier, Dianne; et al. (1997) Knowledge and Attitude Assessment of Quebec Daycare Workers and Parents Regarding HIV/AIDS and Hepatitis B. Canadian Journal of Public Health, Vol. 88, No. 1, pp. 23- 26. Following the implementation of information sessions for parents and workers in Quebec daycare centers, a large number of participating institutions developed their own proactive policies for care of children infected with HIV and/or HBV.

#### **EPIDEMIOLOGY**

Alter, Miriam J.; Kruszon-Moran, Deanna; Nainan, Omana V.; McQuillan, Geraldine M.; Gao, Fengxiang; Moyer, Linda A.; Kaslow, Richard A.; Margolis, Harold S. (1999) **The Prevalence of Hepatitis C Virus Infection in the United States, 1988 Through 1994.** The New England Journal of Medicine, Vol. 341, pp. 556-562.

The authors performed antibody tests for HCV on 21,241 persons 6 years or older who participated in the 3rd NHANES, which was conducted from 1988-1994. Overall prevalence of HCV was 1.8%--corresponding to an estimated 3.9 million persons nationwide. 74% were positive for HCV RNA, indicating that 2.7 million Americans were chronically infected, of whom 73.7% were infected with genotype 1. Strongest independent factors associated (among 17-59 year olds) were illegal drug use and high-risk sexual behavior.

Armstrong, Gregory L.; Alter, Miriam J.; McQuillian, Geraldine, M.; Margolis, Harold S. (2000) The Past Incidence of Hepatitis C Virus Infection: Implications for the Future Burden of Chronic Liver Disease in the United States. Hepatology, Vol. 31, No. 3, pp. 777-782.

Using mathematical modeling, the authors project the future burden of HCV in the United States. The model showed a period of low incidence before 1965, a transition period from 1965 to 1980, and a period of high incidence in the 1980s. The authors conclude prevalence of HCV may be declining because of the decline in incidence in the 1990's; but the number of persons infected for 20 or more years may increase substantially before peaking in 2015.

Broers, Barbara; Junet, Christian; Bourquin, Michel; et al. (1998) Prevalence and incidence rate of HIV, hepatitis B and C among drug users on methadone maintenance treatment in Geneva between 1988 and 1995. AIDS, Vol. 12, pp. 2059-2066.

A cohort of drug users in methadone maintenance therapy in Geneva, Switzerland was tested over time for HIV, HBV, and HCV infection. The prevalence of all three viruses at entry to the program declined markedly over time. Comparing those who entered before 1988 versus those who entered after 1993 by which time extensive prevention outreach had been undertaken, HIV sero-prevalence rates dropped from 38.2% to 4.5%, HBV rates from 80.5% to 20.1%, and HCV rates from 91.6% to 29.8%. "The data suggest that [drug users] have changed HIV risk-taking behavior in response to HIV prevention campaigns."

## **ABBREVIATIONS**

**AIDS** Acquired

Immunodeficiency Syndrome

**HAV** Hepatitis A Virus

**HBV** Hepatitis B Virus

**HCV** Hepatitis C Virus

HIV Human

Immunodeficiency

Virus

IDU Injecting Drug

Use/User

MSM Men who have sex

with Men

STD Sexually Transmitted

Diseases

The Integration of Viral Hepatitis into HIV/AIDS Programs:

Cattaneo, C.; Nuttall, P.A.; Molendinik L.O.; et al. (1999) Prevalence of HIV and hepatitis C markers among a cadaver population in Milan. Journal of Clinical Pathology, Vol. 52, pp. 267-270.

A substantial number of cases in a study of cadavers in Milan had no identifiable risk for HIV or HCV but were infected with one or the other, suggesting that there may be a large unrecognized pool of potential infection.

Gilson, Richard J.C.; Hawkins, Anna E.; Beecham, Michael R. (1997) Interactions between HIV and hepatitis B virus in homosexual men: effects on the natural history of infection. AIDS, Vol. 11, pp. 597-606.

Response in: Bonacini, M. (1997) Interaction between HIV and hepatitis B (letter). AIDS, Col. 11, No. 14, pp. 1789-1790.

A natural history study by Gilson et al. (1997) indicates that HIV infection is associated with higher HBV DNA polymerase activity in HBV carriers. HIV infection increases HBV replication, leading to increased and prolonged HBV i nfectivity. However, it also suggests that HIV-related immunosuppression gives rise to less active liver disease. (There was no evidence of an important effect of HBV carriage on HIV disease progression.) However, this finding was challenged in a letter to the editor by Bonacini (1997) citing evidence "against the theory that HIV leads to intrahepatic immunosuppression."

Gore, S.M.; Brettle, P.; Burns, S.M.; et al. (1998) Early Mortality of Undiagnosed but Prevalent (in 1983-1984) HIV Infection in Lothian Injectors who Tested Hepatitis B Surface Antigen Positive (Group A) or Negative but were High Risk for Blood-borne Virus Transmission (Group B) in 1983-1984. Journal of Infection, Vol. 37, pp. 166-172.

This epidemiological study tracked mortality rates among inmates affected by a 1983-1984 outbreak of HIV and HBV in Scotland. An high early death rate (i.e., death within two years of HIV infection) of 10% was identified among HIV-infected injectors. Since HIV and HBV infection was likely to have occurred at the same time, it is possible that the simultaneous co-infection influenced the rapid progression to death.

Heinen, Michael N.; Lloyd, Larry (1997) HIV, Hepatitis B, and Hepatitis C in the Code One Trauma Population. The American Surgeon, Vol. 63, No. 7, pp. 657-659. Code One trauma patients (i.e., those with an immediate threat to life or limb) revealed higher levels of HIV (0.52%), HBV (1.5%) and HCV (13.8%) than in the overall trauma population or the general population.

Hope, Vivian D.; Judd, Ali; Hickman, Matthew; Lamagni, Theresa; Hunter, Gillian; Stimson, Gerry V.; Jones, Steve; Donovan, Linda; Parry, John V.; Gill, O.N. (2001) Prevalence of Hepatitis C Among Injection Drug Users in England and Wales: Is Harm Reduction Working? American Journal of Public Health, Vol. 91, No. 1, pp. 38-42.

A cross-sectional study surveying drug users who injected in the previous 4 weeks was conducted at drug agencies (n=2203) and in the community (n=758). The prevalence was 30% for anti-HCV, 21% for anti-HBV, and 0.9% for HIV antibodies. Forty-six percent of the sample had injected for less than 6 years. The 30% prevalence of HCV was much lower than in other studies. Among those who had been injecting for less than 3 years, the prevalence was 7.4%, and the estimated incidence among those who had begun injecting in the previous 2 years was below 5.0%. The findings suggest that the prevalence of HCV infection among IDUs in England and in Wales is lower than in other industrialized countries.

Ippolito, Guiseppe; Puro, Vincenzo; Petrosillo, Nicola; et al. (1998) Simultaneous Infection with HIV and Hepatitis C Virus Following Occupational Conjunctival Blood Exposure. JAMA, Vol. 28, No. 1, p. 28.

This case study indicated that simultaneous occupational infection with HIV and HCV led to rapid hepatic failure and death. The authors speculate that acute co-infection could "interfere with initial immune response to HIV and higher HIV burden and more rapid HIV progression."

Lorvick, Jennifer; Kral, Alex H.; Seal, Karen; Gee, Lauren; Edlin, Brian R. (2001) **Prevalence and Duration of Hepatitis C Among Injection Drug Users in San Francisco, Calif.** American Journal of Public Health, Vol. 91, No. 1, pp. 46-47.

The Integration of Viral Hepatitis into HIV/AIDS Programs:

372 stored serum samples collected in 1987 from injection drug users participating in an HIV prevalence and risk behavior study conducted in San Francisco, CA were tested for HCV antibody using the ELISA test. 353 (95%) tested positive for HCV antibody. Of those injecting 2 years or less, 75.9% were infected. Of those injecting for more than 10 years, 98.8% were infected.

Malliori, M.; Sypsa, V.; Psichogiou, M; et al. (1998) **A survey of bloodborne viruses and associated risk behaviors in Greek prisons.** Addiction, Vol. 93, No. 2, pp. 243-251.

A study among 544 drug users imprisoned for drug-related offenses in Greece found that only one was HIV-positive (.19%), but 58.2% had hepatitis C antibodies and 57.6% had hepatitis B antibodies. [See also: Wada, below]

Mast, Eric E. & Alter, Miriam J. (1999) Viral Hepatitis A, B, and C in the Newborn Infant. Seminars in Pediatric Infectious Diseases, Vol. 10, No. 3, pp. 201-207.

This epidemiology, clinical features, diagnosis, treatment, and prevention of hepatitis A, B, and C in newborn infants is discussed. Viral hepatitis in infants is not often recognized because infected infants are usually asymptomatic, but it can be devastating: infants infected with HBV and HCV usually develop chronic infection.

Newell, A.; Nelson, M. (1998) **Infectious hepatitis in HIV-seropositive patients**. International Journal of STD & AIDS, Vol. 9, pp. 63-69.

A review article covering a broad range of aspects of HIVviral hepatitis coinfection. [Note: this article includes 116 references.]

Pallas, J.; Farinas-Alvarez, C.; Prieto, D. et al; (1999) Risk factors for monoinfections and coinfections with HIV, hepatitis B and hepatitis C viruses in northern Spanish prisoners. Epidemiology of Infectious Diseases, Vol. 123, pp. 95-102.

Among a cohort of Spanish prisoners, coinfections with HIV, HBV, and HCV were more common than monoinfections. Risk of coinfection rose with history of IDU and with duration of incarceration.

Pallas, Jose R,; Farinas-Alvarez, Concepcion; Prieto, Dolores, et al. (1999) **Coinfections by HIV, hepatitis B and hepatitis C in imprisoned injecting drug users.** European Journal of Epidemiology, Vol. 15, pp. 699-704.

Among 362 Spanish prisoners, HBV-HCV coinfection was higher, at 42.5%, than HIV-HBV-HCV coinfection (37.3%), while monoinfections were uncommon (overall 13%). Long-term IDU and re-incarceration were the foremost risk factors for coinfections.

Rosenberg, Stanley D.; Goodman, Lisa A.; Osher, Fred C.; Swartz, Marvin S.; Essock, Susan M.; Butterfield, Marian I.; Constantine, Niel T.; Wolford, George L.; Salyers, Michelle P. (2001) **Prevalence of HIV, Hepatitis B, and Hepatitis C in People With Severe Mental Illness.** American Journal of Public Health, Vol. 91, No. 1, pp. 31-37.

Participants undergoing inpatient (n=323) or outpatient (n=608) treatment for mental illness in Connecticut, Maryland, New Hampshire, and North Carolina were tested for HIV, HBV, and HCV. The prevalence of HIV infection in the sample was 3.1%, which is 8 times the estimated US population rate. Prevalence rates of HBV (23.4%) and HCV (19.6%) were approximately 5 and 11 times the overall estimated population rates for these infections, respectively.

Staples, C.T.; Rimland, D.; Dudas, D. (1999) Hepatitis C in the HIV (Human Immunodeficiency Virus) Atlanta V.A. (Veterans Affairs Medical Center) Cohort Study (HAVACS): The Effect of Coinfection on Survival. Clinical Infectious Diseases, Vol. 29, pp. 150-154.

A univariate analysis of a cohort of HIV-positive patients found that those co-infected with HCV were more likely to be older, positive for HBV antibodies and report IDU. However, length of survival and overall disease progression among people with HIV did not appear to be influenced by HCV status. [Note: the study was based on data collected 1992-1997; survival rates for individuals with HIV have changed dramatically since that time.]

Vellinga, A.; Van Damme, P.; Meheus, A. (1999) **Hepatitis B and C in institutions for individuals with intellectual disability.** Journal of Intellectual Disability Research, Vol. 43, Part 6, pp. 445-453.

A review of the literature on HBV and HCV prevalence, risk factors, transmission, and prevention among individuals with intellectual disability.

## **ABBREVIATIONS**

AIDS Acquired Immunodeficiency Syndrome

HAV Hepatitis A Virus

HBV Hepatitis B Virus

**HCV** Hepatitis C Virus

HIV Human Immunodeficiency Virus

IDU Injecting Drug Use/User

MSM Men who have sex with Men

STD Sexually Transmitted Diseases

Wasley, AnneMarie & Alter, Miriam J. (2000) **Epidemiology of Hepatitis C: Geographic Differences and Temporal Trends.** Seminars in Liver Disease, Vol. 20, No. 1, pp. 1-16. Three distinct transmission patterns of HCV were found ooking at age-specific, global prevalence data. Much of the variability was explained by the different risk factors contributing to HCV. The United States falls in the first pattern in which most infections are found among persons 30-49 years and occurred within the recent past (10-30 years); in these countries, injection drug use has been the greatest risk factor. Effective prevention efforts hinge on determining the epidemiology of HCV infection in countries where data has not yet been assessed.

#### **PREVENTION**

Alter, Miriam J. & Moyer, Linda A. (1998) The Importance of Preventing Hepatitis C Virus Infection Among Injection Drug Users in the United States. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, Vol. 18 (Suppl 1), pp. S6-S10.

Forty-three percent of persons with newly acquired HCV during the past 5 years reported injecting street drugs during the 6 months before the onset of illness. HCV appears to be transmitted rapidly after initiating injection, which suggests that prevention efforts should target young IDUs. The authors suggest the following prevention strategies: prevention of the initiation of injection drug use; abstaining from injection drug use; substance abuse treatment; the use of sterile syringes; abstaining from sharing syringes and drug preparation equipment with other IDUs; and changing prescription and pharmacy laws to provide reliable sources for IDUs to obtain sterile syringes.

American Association of Colleges of Nursing (1997) Policy and Guidelines for Prevention and Management of Human Immunodeficiency Virus and Hepatitis B Virus Infection in the Nursing Education Community. Journal of Professional Nursing, Vol. 13, No. 5, pp. 325-328.

Health care workers are at risk for both HIV and HCV. Policy guidelines established by the American Association of Colleges of Nursing (1997) recognize the dangers of both viruses. Noting that HBV kills 200 health care workers annually, the policy calls for mandatory HBV vaccination.

American Medical Association, Council on Scientific Affairs (1996) **Health Care Needs of Gay Men and Lesbians in the United States.** JAMA, Vol. 275, No. 17, pp. 1354-1355.

This American Medical Association policy statement on "Health Care Needs of Gay Men and Lesbians in the United States" states that "all forms of hepatitis can occur in gay male patients. Because of the risk for hepatitis B infection, sexually active gay and bisexual men should receive the hepatitis B vaccine. In general, gay men are at greater risk for contracting hepatitis B than hepatitis C virus infection, which is frequently transmitted by injecting drugs."

Borg, Lisa; Khuri, Elizabeth; Wells, Aaron; et al. (1999) Methadone-maintained former heroin addicts, including those who are anti-HIV-1 seropositive, comply with and respond to hepatitis B vaccination. Addiction, Vol. 94, No. 4, pp. 489-493.

Despite complications, it is possible to achieve compliance with the three-shot course of hepatitis B vaccination. Among cohort of HIV-positive former heroin addicts in methadone maintenance, 86% completed the six-month vaccination series.

Cassidy, William M; Mahoney, Frank J. (1995) A Hepatitis B Vaccination Program Targeting Adolescents. Journal of Adolescent Health, Vol. 17, pp. 244-247.

After an educational campaign and a program of in-school vaccinations, two-thirds of a middle school population received the full three doses of the hepatitis B vaccine. Of those without pre-existing immunity to HBV, 96% developed protective levels of antibodies to HBV.

Cockcroft, A.; Elford, J. (1994) Clinical practice and the perceived importance of identifying high risk patients. Journal of Hospital Infection. Vol. 28, pp. 127-136.

A survey of British health care providers revealed that those who believed they could identify patients at high risk for HIV or viral hepatitis were less likely to practice universal precautions. The article argues that effective implementation of universal precautions requires addressing underlying beliefs among health care workers.

Crampin, A.C.; Lamagne, T.L.; Hope, V.D.; et al. (1998) **The risk of infection with HIV and hepatitis B in individuals who inject steroids in England and Wales.** Epidemiology of Infectious Disease, Vol. 121, pp. 381-386.

A British cohort of injectors of anabolic steroids had dramatically lower levels of HIV and HBV than cohorts of heroin or amphetamine injectors, and also rarely shared needles, suggesting the need to treat steroid injectors differently than other IDUs.

Crofts, Nick; Nigro, Luciano; Oman, Kimberely; et al. (1997) **Methadone maintenance and hepatitis C virus infection among injecting drug users.** Addiction, Vol. 92, No. 8, pp. 999-1005.

This article argues that the value of methadone maintenance therapy for HCV prevention is unclear, given that although such programs do decrease injection episodes even a single relapse into injecting behavior can lead to transmission due to the high efficiency of HCV transmission. "Patients who are seropositive for HCV need counseling about all aspects of their infection, including methods to minimize the risk of further transmission. This counseling must emphasize not sharing any injecting equipment or allowing any blood contamination of objects or surfaces which can carry the virus to others." This advice is relevant for both HCV-positive and HCV-negative patients due to the risk of reinfection with other subtypes of HCV.

Diaz, Theresa; Des Jarlais, Don C.; Vlahov, David; Perlis, Theresa E.; Edwards, Vincent; Friedman, Samuel R.; Rockwell, Russell; Hoover, Donald; Williams, Ian T.; Monterroso, Edgar R. (2001) Factors Associated With Prevalent Hepatitis C: Difference Among Young Adult Injection Users In Lower and Upper Manhattan, New York City. American Journal of Public Health, Vol. 91, No. 1, pp. 23-30.

Correlates of prevalent HCV infections among young adult IDUs in 2 neighborhoods in New York City were examined. Participants were recruited from the Lower East Side and Harlem. In both sites, testing positive for HCV antibody was associated with having injected for more than three years. Participants were asked about drug use and sexual behaviors and the authors found several differences in factors associated with prevalent HCV infection among two populations of young injection drug users from the same city.

Hagan, Holly; Thiede, Hanne; Weiss, Noel S.; Hopkins, Sharon G.; Duchin, Jeffrey S.; Alexander, E.R. (2001) **Sharing of Drug Preparation Equipment as a Risk Factor for Hepatitis C.** American Journal of Public Health, Vol. 91, No. 1, pp. 42-46.

The risk for HCV infection from sharing cookers, cotton, and water used to prepare drugs for injection was examined, and it was found that among injection drug users who do not share syringes, 54% of HCV infections were attributable to sharing cookers and cotton.

Hagan, Holly; Des Jarlais, Don C.; Freidman, Sam R.; Purchase Dave; Alter, Miriam J. (1995) Reduced risk of hepatitis B and C among injection drug users in the Tacoma syringe exchange program. American Journal of Public Health, Vol. 85, pp. 1531-37.

This case-control study found that non-use among injectors of the syringe exchange program was associated with a sixfold greater risk of HBV and a sevenfold greater risk of HCV.

Hagan, Holly; McGough, James P.; Thiede, Hanne; Weiss, Noel S.; Hopkins, Sharon; Alexander, E. Russell (1999) Syringe Exchange and Risk of Infection with Hepatitis B and C Viruses. American Journal of Epidemiology, Vol. 149, No. 3, pp. 203-213.

No protective benefit of the Seattle-King County Department of Public Health's needle exchange program on HBV and HCV infection among a cohort of IDUs was found. On average, regular users of the exchange injected more frequently than sporadic- and non-users of the exchange, and reported more high-risk behaviors (i.e. sharing drug preparation equipment, backloading).

Heimer, Robert; Khoshnood, Kaveh; Bigg, Dan; et al. (1998) Syringe Use and Reuse: Effects of Syringe Exchange Programs in Four Cities. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, Vol. 18 (Suppl.), pp. S37-S44.

In four American cities (New Haven, Baltimore, Chicago, and San Francisco), after the introduction of syringe-exchange programs, the average number of injections per syringe was halved and there was a significant rise in once-only use of syringes. There was also a rapid decline in the percentages of syringes that had been used by HIV-or HBV-infected injectors.

## **ABBREVIATIONS**

**AIDS** Acquired

Immunodeficiency Syndrome

**HAV** Hepatitis A Virus

HBV Hepatitis B Virus

**HCV** Hepatitis C Virus

**HIV** Human

Immunodeficiency

Virus

IDU Injecting Drug

Use/User

MSM Men who have sex

with Men

STD Sexually Transmitted

Diseases

Kane, Mark; Meheus, Andre; Van Damme, Pierre (1998) Control of Hepatitis B in Europe: Where Are We in 1997? Special Issue of Vaccine, Vol. 16, Suppl., pp. S1-S81.

This issue of the journal Vaccine covers HBV issuesincluding the evolution of the Viral Hepatitis Control Board, various European programs, and articles regarding HBV control in Spain, Greece, the US, the UK, and the Scandinaviancountries.

Lawrence, Monique H.; Goldstein, Mark A. (1995) **Hepatitis B Immunization in Adolescents**, Journal of Adolescent Health, Vol. 17, pp. 234-243.

This broad review of HBV vaccination policy in the US tracks the failure of attempts to identify and vaccinate only high risk adolescents. It recommends universal hepatitis B vaccination in a school-based setting during the middle school years, a strategy which could potentially lead to eradication of hepatitis B in the United States.

Lurie, Peter; Fernandes, Maria Eugenia Lemos; Hughes, Veronica; et al. (1995) Socioeconomic status and risk of HIV-1, syphilis and hepatitis B infection among sex workers in Sao Paulo State, Brazil. AIDS, Vol. 9, Suppl. 1, pp. S31-S37.

A study of socioeconomic status (SES) among sex workers in Brazil (Lurie et al., 1997) found a strong correlation between SES and disease acquisition. Those with higher as opposed to lower SES had lower rates of HIV (4% vs. 17%), syphilis (24% vs. 66%), and HBV (26% vs. 52%).

Marron, Rebecca L.; Lanphear, Bruce P.; Kouides, Ruth; et al. (1998) Efficacy of Informational Letters on Hepatitis B Immunization Rates in University Students. College Health, Vol. 47, pp. 123-127.

Informational letters sent to a group of college students led 10.7% to receive HBV immunizations (vs. 1.9% in a control group). Students at higher risk for HBV were more likely to be go for an immunization.

Mast, Eric E.; Mahoney, Frank J.; Alter, Miriam J., et al. (1998) **Progress toward elimination of hepatitis B virus transmission in the United States**. Vaccine, Vol. 16, pp. S48-S51.

An overview by CDC officials, this article reviews progress in implementing the national strategy to eliminate HBV. Goals for the program, which had in 1998 been met to varying

degrees, included: 1) preventing perinatal transmission; 2) routine infant vaccination; 3) catch-up vaccination of children in high risk groups at all ages; 4) catch-up vaccination of all children ages 11-12; and 5) vaccination of adults and adolescents in high risk groups. At the time of writing, emphasis was on improving complete immunoprophylaxis of infants born to mothers with HBV, increasing vaccine coverage among children ages 11-12, and implementing vaccination programs for high risk adults and adolescents.

Mast, Eric E.; Alter, Miriam J.; Margolis, Harold S. (1999) **Strategies to prevent and control hepatitis B and C virus infections: A global perspective**. Vaccine, Vol. 17, pp. 1730-1733.

Approximately 30% of the world's population is infected with HBV; the authors emphasize the importance of preventing perinatal transmission, providing routine child-hood vaccination and vaccinating high-risk groups, and preventing nosocomial transmission. An estimated 3% of the world's population is infected with HCV; the authors stress the importance of utilizing primary prevention strategies which target nosocomial risks and high-risk behaviors (i.e. injection drug use, unprotected sex with multiple partners) and using secondary prevention strategies (i.e. medical management, abstaining from alcohol) to reduce the risk for liver disease.

Moor, A.C.E.; Dubbelman, T.M.A.R.; VanSteveninck, J; et al. (1999) **Transfusion-transmitted diseases: risks, prevention and perspectives.** European Journal of Haematology, Vol. 62, pp. 1-18.

While the introduction of blood donor counseling and screening has significantly reduced rates of bloodborne pathogens in the blood supply, there is still some possibility for HIV or viral hepatitis to enter the blood supply. However, new technologies (e.g., polymerase chain reaction) are expected to continue to reduce this risk in the developed world, where they are affordable, but not necessarily in the developing world. [Note: this article includes 183 references.]

Moore-Caldwell, Sharon Y.; Werner, Mark J.; Powell, Laura; et al. (1997) **Hepatitis B Vaccination in Adolescents: Knowledge, Perceived Risk, and Compliance.** Journal of Adolescent Health, Vol. 20, pp. 294-299.

Moore-Caldwell et al. (1997) determined that adolescents had little knowledge of HBV but that parents were better informed, and the more informed parents are about HBV, the lower the reported level of risk-taking behaviors among adolescents.

Neighbors, Katie; Oraka, Chinwe; Shih, Linda; et al. (1999) Awareness and Utilization of the Hepatitis B Vaccine Among Young Men in the Ann Arbor Area Who Have Sex with Men. College Health, Vol. 47, pp. 173-178.

In a study of MSM in a college town, two-thirds were aware of a hepatitis B vaccine, but only one-fifth had received the full three-dose series. Respondents expressed willingess to be vaccinated, a task which could be undertaken by university health services in a college-town setting.

O'Connor, J. Barry; Imperiale, Thomas F.; Singer, Mendel E. (1999) Cost-Effectiveness Analysis of Hepatitis A Vaccination Strategies for Adults. Hepatology, Vol. 30, No. 4, pp. 1077-1081.

In a cost-effectiveness study, mass hepatitis A vaccination of the general population was determined not to be cost-effective, but could be for particular areas or populations in which hepatitis A is endemic.

Panda, S.; Chatterjee, A.; Bhattacharjee, S.; et al. (1998) HIV, hepatitis B and sexual practices in the street-recruited injecting drug users of Calcutta: risk perception versus observed risks. International Journal of STD & AIDS, Vol. 9, pp. 214-218.

A male IDU research cohort in Calcutta was 20% HBV antigen positive. Condom use was rare even though nearly three-quarters reported sex with prostitutes and nearly 90% had shared needles.

Resti, Massimo; Azari, Chiara; Mannelli, Francesco; et al. (1998) Mother to child transmission of hepatitis C virus: prospective study of risk factors and timing of infection in children born to women seronegative for HIV-1. BMJ, Vol. 37, pp. 437-441.

HCV can be transmitted perinatally; 13 of 403 children born to HCV positive/HIVnegative women became infected with HCV.

# **ABBREVIATIONS**

**AIDS** Acquired Immunodeficiency

Syndrome

Hepatitis A Virus

Hepatitis B Virus

HAV

HBV

IDU

HCV Hepatitis C Virus

HIV Human Immunodeficiency Virus

Injecting Drug

Use/User

MSM Men who have sex

with Men

STD Sexually Transmitted

**Diseases** 

Romanowski, Barbara; Campbell, Patricia J.; Preiksaitis, Jutta K.; et al. (1997) Human Immunodeficiency Virus Seroprevalence and Risk Behaviors in Patients Attending Sexually Transmitted Disease Clinics in Alberta. Sexually Transmitted Diseases, Vol. 24, No. 8. pp. 487-494.

This study of Canadian STD clinic attendees revealed a prevalence of 1.5% for HIV and 3.4% for HCV; prevalence of both viruses was associated with IDU and exchanging sex for money or IDU.

Seage III, George R.; Mayer, Kenneth; Lenderking, William R. (1997) HIV and Hepatitis B Infection and Risk Behavior in Young Gay and Bisexual Men. Public Health Reports, Vol. 112, pp. 158-167.

Among a cohort of 390 young MSM in Boston, HIV and HBV prevalence were low. Intervention was called for among those most likely to have unprotected anal intercourse, notably those with histories of STDs, alcohol abuse and depression.

Shriver, Mike; de Burger, Ron; Brown, Christopher; et al. (1998) Bridging the Gap between Science and Practice: Insight to Researchers from Practitioners. Public Health Reports, Vol. 113, Suppl. 1, pp. 189-193. practitioners Policy advocates and provide recommendations for researchers to facilitate the translation of research on IDUs into practice at the programmatic level. Recommendations discuss access and dissemination issues, developing user-friendly publications, forging partnerships outside the research arena, taking the research into the field, and challenges for the future. The authors note: "If researchers do not take the time to translate HIV prevention science into usable information for people at the implementation. government, and policy levels, then this vital HIV prevention information will have little or no positive impact on policy, programs, or funding."

Sloboda, Zili (1998) What We Have Learned from Research about the Prevention of HIV Transmission among Drug Abusers. Public Health Reports, Vol. 113, Suppl. 1, pp. 194-204.

A review of research into prevention interventions among drug abusers revealed that successful interventions engage abusers, specify target behaviors and attitudes for intervention, suggest useful settings, and recommend booster approaches.

Smyth, Bobby P.; Kennan, Eamon; O'Connor, John J. (1999) Evaluation of the impact of Dublin's expanded harm reduction programme on prevalence of hepatitis C among short-term injecting drug users. Journal of Epidemiology and Community Health, Vol. 53, pp. 435-435. An expansion of harm reduction services to IDUs (i.e., increased number of needle exchange programs, outreach workers, and counselors) was followed by a twofold reduction in the likelihood of HCV infection.

Stark, Klaus; Muller, Reinhold; Beinzle, Ulrich; et al. (1996) Frontloading: a risk factor for HIV and hepatitis C virus infection among injecting drug users in Berlin. AIDS, Vol. 10 pp., 311-317.

In a cohort of 324 IDUs in Berlin, 84% had practiced frontloading (i.e., two or more IDUs using one syringe to prepare a drug solution before sharing it) with non-sterile equipment; more than half of those had done so over 100 times. Seroprevalence rates for HIV, HBV and HCV increased with number of frontloading, with HCV rates reaching as high as 94%. The article notes that even in localities with sterile syringe access and/or needle exchange programs, frontloading may still constitute a significant public health threat.

Strathdee, Steffanie A.; Patrick, David M.; Currie, Sue L.; et al. (1997) **Needle exchange is not enough: lessons from the Vancouver injecting drug use study.** AIDS, Vol. 11, pp. F59-F65.

Strathdee et al. (1997) conducted a study with a prospective cohort of injecting drug users in Vancouver, Canada, which has had a needle exchange program (NEP) since 1988 and distributes 2 million needles annually. Although 93% had attended the NEP, HIV seroprevalence was 23% and HCV seroprevalence was 88%. "Whereas NEP are crucial for sterile syringe provision, they should be considered one component of a comprehensive program including counseling, support, and education."

Thorpe, Lorna E.; Ouellet, Lawrence J.; Levy, Jennie R.; Williams, Ian T.; Monterroso, Edgar R. (2000) **Hepatitis C Virus Infection: Prevalence, Risk Factors, and Prevention Opportunities among Young Injection Drug Users in Chicago,** 1997-1999. The Journal of Infectious Diseases, Vol. 182, pp. 1588-1594.

An HCV prevalence of 27% was found in a sample of 698 adult IDUs (18-30yrs) in Chicago. HCV infection was strongly associated with age and years injecting. Seventy-five percent of the sample reported initiating injection within the last 4 years. This study found a lower prevalence among IDUs than previously reported, emphasizing the need for prevention efforts to target young, newer IDUs.

Van Beek, Ingrid; Dwyer, Robin; Dore, Gregory J.; et al. (1998) Infection with HIV and hepatitis C virus among injecting drug users in a prevention setting: retrospective cohort study. BMJ, Vol. 317, pp. 433-437. Response in: Coutinho, R.A. (1998) HIV and hepatitis C among injecting drug users: Success in preventing HIV has not been mirrored for hepatitis C (letter).

BMJ, Vol. 317, pp. 424-425.

Van Beek et al. (1998) conducted a retrospective cohort study of injecting drug users in a primary healthcare facility in Australia and revealed that HIV seroincidence was 0.17 per 100 person years but that HCV seroincidence was more than 100 times greater at 20.9 per 100 person years – and 75.6 per 100 person years among those aged less than 20 years. In an editorial commentary on the study, Coutinho (1998) noted that "success in preventing HIV has not been mirrored for hepatitis C." Noting the greater efficiency of bloodborne transmission of HCV than HIV and higher population seroprevalence rates of HCV than HIV, he notes that prevention messages crafted for HIV are insufficient for HCV among injecting drug users and that prevention messages should be expanded to include "indirect" sharing of cotton, water, and other equipment. This is the case even in Australia, which has had expansive harm reduction policies in place.

Vidal-Trecan, Gwenaelle; Coste, Joel; Varescon-Pousson, Isabelle; et al. (1998) Patterns of sexual and injecting risk behaviors in French intravenous drug users not reporting HIV and hepatitis C virus seropositives. Addiction, Vol. 93, No. 11, pp. 1657-1668.

A study of French intravenous drug users not reporting being infected with HIV or HCV reports numerous overlapping risk behaviors which could lead to HIV and HCV seroconversion, including lending and borrowing of drug

paraphernalia, inconsistent use of condoms, having multiple partners and/or engaging in prostitution, and not using clean needles. Associated behaviors and characteristics included alcohol abuse, homelessness, low educational level, and cocaine use.

Wada, Kiyoshi; Greberman, Sharyn Bowman; Konuma, Kyohei, et al. (1999) **HIV and HCV infection among drug users in Japan.** Addiction, Vol. 94, No. 7, pp. 1063-1070. A study of 32 inpatients in a Japanese substance treatment facility found that none were HIV-positive but 53.8% of methamphetamine-dependent patients had hepatitis C, as did 18.4% of solvent-dependent patients and 5.6% of alcohol-dependent patients. [See also: Malliori, above]

# **Appendix B:**

Leave the Surfing to Us: Quick Links to Frequently Sought Information

Even the most experienced Web surfer can find it a challenge to navigate the ever increasing universe of Websites. So NASTAD has gone ahead and created a list of "quick links" that will bring you directly to some of the more frequently sought types of information about HIV and viral hepatitis. You can type in the links listed below, or access live links on the NASTAD Website by visiting <a href="http://www.nastad.org/pro\_viral\_hepatitis.asp?menu=pro">http://www.nastad.org/pro\_viral\_hepatitis.asp?menu=pro</a> and by scrolling down to and then clicking on Links for Frequently Sought Information regarding Viral Hepatitis.

For the latest news on viral hepatitis and HIV co-infection:

http://www.hivandhepatitis.com

For frequently asked questions and answers on viral hepatitis and HIV co-infection:

http://www.cdc.gov/hiv/pubs/facts/HIV-HCV\_coinfection.htm

For conference reports on viral hepatitis and HIV coinfection:

Summaries:

http://www.hivandhepatitis.com/int\_conf\_rpt.html

Full text:

http://www.hivandhepatitis.com/teleconf.html

For a report on state-of-the-art treatments for hepatitis:

http://www.hepb.org/drugwatch.html

For the NIH Consensus Statement on the Management of Hepatitis C:

http://odp.od.nih.gov/consensus/cons/105/105\_statement.htm

For information on liver health:

http://www.liverfoundation.org/html/livheal.dir/livheal.htm

For medical news and information on hepatitis: http://www.docguide.com/news/content.nsf/PatientResAllcateg/Hepatitis? Opendocument

For information on HIV, HBV, and HCV clinical trials: http://www.veritasmedicine.com/

For information on hepatitis clinical trials: http://www.centerwatch.com/studies/cat79.htm

For the National Hepatitis C Prevention Strategy: http://www.cdc.gov/ncidod/diseases/hepatitis/c/plan/index.htm

For the Texas Department of Health's Hepatitis C Prevention Counseling Training:

http://www.tdh.state.tx.us/hivstd/educate/hepc/default.htm

For Model Programs for Hepatitis A, B, & C Prevention: http://www.hepprograms.org

For information on Hepatitis C disease management: http://www.niddk.nih.gov/health/digest/pubs/chrnhepc/chrnhepc.htm

For information about Hepatitis A and B vaccinations: http://www.niddk.nih.gov/health/digest/pubs/vacc4hep/vacc4hep.htm

For state-by-state laws regarding Hepatitis B vaccinations: http://www.immunize.org/laws/hepb.htm

For information about Hepatitis B vaccinations among health care workers:

http://www.immunize.org/catg.d/2109hcw.htm

For state-by-state listings of hepatitis support groups: http://www.hepfi.org/US-Cities.htm#MN

For information about pediatric viral hepatitis: http://www.pkids.org/hepatitis.htm

For publications on health care in prisons: http://www.ncchc.org/publication.html#pubs

For information about viral hepatitis among Asians and Pacific Islanders:

http://www.aapihp.com/hepbtf/default.asp

## Para informacion en Español:

Sobre la Hepatitis A:

http://www.niddk.nih.gov/health/digest/pubs/hep/hepaspn/index.htm Sobre la Hepatitis B:

http://www.niddk.nih.gov/health/digest/pubs/hep/hepbspn/index.htm Sobre la Hepatitis C:

http://www.niddk.nih.gov/health/digest/pubs/hep/hepcspn/index.htm

For information about the international work of the Viral Hepatitis Prevention Board:

http://www.vhpb.org/

For an on-line CDC training on hepatitis C:

http://www.cdc.gov/ncidod/diseases/hepatitis/C\_Training/edu/default.htm

For CDC's Morbidity and Mortality Weekly Report (MMWR) articles on viral hepatitis:

http://www.cdc.gov/ncidod/diseases/hepatitis/resource/pubs.htm

For CDC slide sets on viral hepatitis:

http://www.cdc.gov/ncidod/diseases/hepatitis/slideset/

For brochures on viral hepatitis:

 $\label{lem:http://www.cdc.gov/ncidod/diseases/hepatitis/resource/brochures. htm OR$ 

http://www.hepfi.org/infomenu.htm

OR

http://www.immunize.org/catg.d/free.htm

OR

http://www.liverfoundation.org/html/livheal.dir/livheal.htm

For information about NIH research on viral hepatitis:

http://www.niaid.nih.gov/dir/labs/lid/purcell.htm

For information about the city and county health response to viral hepatitis:

http://www.naccho.org/project41.cfm

For California's Hepatitis C Strategic Plan:

http://www.dhs.ca.gov/ps/dcdc/pdf/Hepatitis%20C%20Strategic%20Plan%20-%202001.pdf

For Maine's Hepatitis C needs assessment, "At the Crossroads: Hepatitis C Infection in Maine":

http://www.state.me.us/dhs/boh/ddc/hepcfull.doc

Appendix C:
The HIV-Viral Hepatitis Connection
A Select Annotated
Bibliography of the

Biomedical Literature

**Public Health and** 

# **ABBREVIATIONS**

**AIDS** Acquired

Immunodeficiency Syndrome

**HAV** Hepatitis A Virus

**HBV** Hepatitis B Virus

**HCV** Hepatitis C Virus

**HIV** Human

Immunodeficiency

Virus

IDU Injecting Drug

Use/User

MSM Men who have sex

with Men

STD Sexually Transmitted

Diseases

Following is a continuation of Appendix A, a select annotated bibliography of the public health literature regarding the connection between infection with HIV and with viral hepatitis.

The articles herein were identified either through a search of articles in major journals with textwords "HIV" and "Hepatitis" in the MedLine and/or PsychInfo database from the period 1994-2000, or through a review of sources NASTAD utilizes. Articles were selected for inclusion based upon their relevance for public health efforts against viral hepatitis within the context of HIV programs. Note that due to delays in indexing, some relevant articles may not be included. Articles are organized under the following 3 subject headings: Care and Treatment, Epidemiology and Prevention.

Readers who are aware of important articles not included in this review are encouraged to send copies to NASTAD's Viral Hepatitis Program at the following address: <a href="mailto:lschowalter@nastad.org">lschowalter@nastad.org</a>.

#### **CARE & TREATMENT**

Leigh, J. Paul; Bowlus, Christopher L.; Leistikow, Bruce N.; and Schenker, Marc (2001) **Costs of Hepatitis C**. Archives of Internal Medicine, Vol. 161, pp. 2231-2237.

The authors estimated the cost of hepatitis C in the United States in 1997 using the prevalence of HCV and chronic liver disease and the human capital and cost-of-illness method, where direct and indirect costs are calculated. Direct costs include medical and administrative expenses while indirect include lost wages, lost fringe benefit, and lost home production. The authors estimate \$5.46 billion as the cost of HCV in 1997, with 33% accounting for direct costs and 67% for indirect costs. HCV that results in chronic liver disease accounts for 92% of the costs while HCV that results in primary liver cancer accounts for 8%.

Wong, John B.; McQuillan, Geraldine M.; McHutchinson, John G; and Poynard, Thierry (2000). **Estimating Future Hepatitis C Morbidity, Mortality, and Costs in the United States**. American Journal of Public Health, Vol. 90, No. 10, pp. 1562-1569.

The authors used a computer simulation to model HCV prognosis by following up over time a cohort representative of the HCV-infected cohorts for each age group within the National Health and Nutritional Examination Survey III. The model predicted 165,900 deaths from chronic liver disease, 27,200 deaths from hepatocellular carcinoma, and \$10.7 billion in medical expenditures for HCV for the years 2010 to 2019. The model predicted that the highest proportion of HCV-related deaths would peak in 2014 and the need for liver transplants would rise until 2015. The model found that HCV may lead to the loss of 1.83 billion years of life in those younger than 65. The model excluded incarcerated populations and did not take into account coinfection with HBV or HIV.

### **EPIDEMIOLOGY**

Beech, Bettina M.; Myers, Leann; Beech, Derrick J. (2002) **Hepatitis B and C Infections among Homeless Adolescents.** Family Community Health, Vol. 25, No. 2, pp. 28-36.

The authors conducted an HBV and HCV seroprevalence study of 150 homeless adolescents in a large southwest city in the U.S. Of the 125 participants with complete data, 27 (22%) were positive for HBV or HCV. Participants positive for hepatitis were significantly older and more likely to be Caucasian. Sexual preference (homosexual/bisexual vs. heterosexual) and lifetime crack use were also strong predictors of hepatitis. This study underscores the importance of reaching high-risk adolescents with hepatitis prevention services.

Murrill, Christopher S.; Weeks, Howard; Castrucci, Brian C.; et al. (2002) Age Specific Seroprevalence of HIV, Hepatitis B Virus, and Hepatitis C Virus Infection Among Injection Drug Users Admitted to Drug Treatment in 6 US Cities. American Journal of Public Health, Vol. 92, No. 3, pp.385-387.

Sera were collected from 1717 IDUs entering treatment in Newark, NJ; Baltimore, MD; Detroit, MI; Denver, CO; San Francisco, CA; and Seattle, WA, from 1993-1994. The authors measured age-specific seroprevalence of HIV, HBV and HCV infection. The prevalence of anti-HBc and anti-HCV was high in all geographic regions, increasing with age and reaching 80-100% among older IDUs in all 6 cities. HIV prevalence also increased with age but peaked at 30% to 40% in Newark and Baltimore and approximately 5% in the other 4 cities. The authors conclude that primary prevention programs, offering vaccination against HBV, access to substance abuse treatment, and access to sterile syringes, should be targeted towards new initiates to injection drug use.

Page-Shafer, Kimberly A.; Cahoon-Young, Barbara; Klausner, Jeffrey D.; et al. (2002) Hepatitis C Virus Infection in Young, Low-Income Women: The Role of Sexually Transmitted Infection as a Potential Cofactor for HCV Infection. American Journal of Public Health, Vol. 92, No. 4, pp. 670-676. The authors measured HCV infection among 1707 young women participating in the Young Women's Survey, which is a cross-sectional, population-based survey used to measure HIV, STDs, and risk behaviors of young (age 18-29 years), lowincome women living in Northern California (San Francisco, Alameda, San Joaquin, and San Mateo counties). authors found a population-based estimate of HCV prevalence in the 4-county area to be 2.5%. HCV prevalence was highest in the two most urban counties. HCV infection was independently associated with a history of injection drug use, herpes simplex virus type 2 (HSV-2) and heroin and cocaine The authors conclude that hepatitis C prevention programs in low-income areas should incorporate substance abuse treatment and STD prevention programs.

Remis, Robert S.; Dufour, Annie; Alary, Michael; et al. (2000) **Association of Hepatitis B Virus Infection With Other Sexually Transmitted Infections in Homosexual Men.** American Journal of Public Health, Vol. 90, No. 10, pp. 1570-1574.

The authors measured the prevalence and factors associated with HBV infection among 625 HIV seronegative MSM in Montreal, Canada. Of the 625 participants, 297 (48%) reported receiving at least one dose of HBV vaccine. Of the 328 men who reported not being vaccinated, 134 (41%) had an HBV marker and 127 (39%) had either HbsAg or anti-HBc. The authors found seven factors independently associated with HBV infection: history of ulcerative STD, injection drug use, history of gonorrhea or chlamydia, having had a partner with HIV or AIDS, 50 or more casual sex partners, received money for sex, and 20 or more regular sex partners.

Samuel, M.C.; Doherty, P.M.; Butlerys, M.; and Jenison, S.A. (2001). Association between heroin use, needle sharing and tattoos received in prison with hepatitis B and C positivity among street-recruited injection drug users in New Mexico, USA. Epidemiological Infection, Vol. 127, pp. 475-484.

The authors assessed the seroprevalence and risk factors for HBV, HCV and HIV of 1003 IDUs recruited from three regions of New Mexico. The overall rate of antibody positivity for HCV was 82.2%, for HBV 61.1%, and 0.5% for HIV. Prevalence of HBV and HCV increased with age; among those 45 years or older, 78.9% were positive for HBV and 89.4% were positive for HCV. The seroprevalence of HBV and HCV was also strongly associated with number of years of injecting; after 30 years or more of injection, 82.5% of participants were positive for HBV and 90.6% were positive for HCV. The authors also found that tattoos acquired in prison were associated with both HBV and HCV infection.

#### **PREVENTION**

Des Jarlais, Don C.; Fisher, Dennis G.; Clark Newman, Jessica; et al. (2001) Providing Hepatitis B Vaccination to Injection Drug Users: Referral to Health Clinics vs. On-Site Vaccination at a Syringe Exchange Program. American Journal of Public Health, Vol. 91, No. 11, pp. 1791-1792.

Two methods for providing free HBV vaccination to IDUs were compared: 1. referral by research staff to local health care providers and 2. on-site vaccination at a syringe exchange program (SEP). Participants at both sites received financial compensation for participants. Thirty-one percent of participants eligible for HBV vaccination at the referral site completed the three dose series, and 83% of the eligible participants at the SEP completed the three dose series. The authors conclude that financial incentives and convenient locations increase adherence to HBV vaccination among IDUs.

Friedman, Michael S.; Blake, Paul A.; Koehler, Jane E.; et al. (2000) Factors Influencing a Communitywide Campaign to Administer Hepatitis A Vaccine to Men Who Have Sex With Men. American Journal of Public Health, Vol. 90, No.12, pp. 1942-1946.

The Georgia Division of Public Health began a hepatitis A vaccine campaign, focused on men who have sex with men, 8 months after a large, ongoing hepatitis A outbreak among MSM was identified in Atlanta. The campaign provided free hepatitis A vaccine for one year at community sites that reach MSM and public health clinics/medical provider practices that serve MSM. The campaign was promoted through gay media, organizations that serve MSM, physicians, and gay-oriented businesses. The authors report the results of a survey of a cohort of MSM, taken from five community sites, measuring the effectiveness of the campaign. participants 178 (85%) were susceptible to hepatitis A and 34 (19%) of those received hepatitis A vaccine during the campaign. The authors found no change in vaccination coverage among those who reported one exposure to campaign information, however; vaccine coverage rates increased linearly as the number of informational exposures increased beyond 1. Routine reading of a local gay newspaper was significantly associated with vaccination.

Goldstein, Susan T.; Alter, Miriam J.; Williams, Ian T., et al. (2002) Incidence and Risk Factors for Acute Hepatitis B in the United States, 1982-1998: Implications for Vaccination Programs. The Journal of Infectious Diseases, Vol. 185, pp. 713-719.

The authors examined changes in disease incidence and risk factors for acute HBV during 1982-1998 in four U.S. counties: Jefferson County (Birmingham), Ala.; Denver County (Denver), Colo.; Pinellas County (St. Petersburg), Fla.; and Pierce County (Tacoma), Washington. A total of 3,937 cases of acute HBV were reported. The highest incidence occurred in 1987 (13.8 cases per 100,000 population) and declined by 76.1% to 3.3 per 100,000 in 1998. Heterosexual exposure to an infected partner or to multiple

# **ABBREVIATIONS**

**AIDS** Acquired

Immunodeficiency

Syndrome

**HAV** Hepatitis A Virus

HBV Hepatitis B Virus

**HCV** Hepatitis C Virus

HIV Human

Immunodeficiency

Virus

IDU Injecting Drug

Use/User

MSM Men who have sex

with Men

STD Sexually Transmitted

**Diseases** 

partners (27.4%), IDU (18.2%), and MSM activity (13.5%) were the predominant risk factors, accounting for 88.3% percent of cases where risk could be identified. In 1996 investigators began to collect data on lifetime history of both STDs and found incarceration and of 236 patients interviewed, 84 (35.6%) reported prior treatment for an STD and 68 (28.8%) reported incarceration. In all, 110 (46.6%) reported one of these factors, and 21 (8.9%) reported both. The authors note that STD clinics and correctional facilities present missed opportunities for HBV vaccination; vaccination programs in those settings had the potential to prevent about one-half of new infections. The authors conclude that HBV cannot be eliminated until there is a nationwide program to vaccinate adults at increased risk for HBV.

Mackellar, Duncan A.; Valleroy, Linda A.; Secura, Gina M.; et al. (2001) **Two Decades After Vaccine License: Hepatitis B Immunization and Infection Among Young Men Who Have Sex With Men**. American Journal of Public Health, Vol. 91, No. 6, pp. 965-971.

The authors investigated hepatitis B immunization coverage and HBV infection among young MSM through the Young Men's Survey (YMS), which is a cross-sectional, anonymous, survey of young MSM. Data from 3432 randomly selected aged 15-22 years, were collected at gay-identified venues in 7 U.S. metropolitan areas from 1994-1998. The authors found that 9% of the participants had been immunized against HBV, 11% had evidence of HBV infection, and 77% were susceptible to infection. prevalence of HBV infection increased by age for all racial/ethnic minority groups. The authors found that although 9 out of 10 young MSM reported using a regular source of health care, only 1 in 10 had been immunized, suggesting that providers are missing opportunities to vaccinate persons at risk for HBV. Fewer than one in ten participants reporting a previous STD had been immunized, and nearly two-thirds of susceptible MSM had been previously tested for HIV, again suggesting missed opportunities for vaccination. The authors recommend integration of HBV prevention into HIV-STD prevention programs.

Udeagu Pratt, Chi-Chi N.; Paone, Denise; Carter, Rosalind J.; and Layton, Marcelle C. (2002). **Hepatitis C Screening and Management Practices: A Survey of Drug Treatment and Syringe Exchange Programs in New York City.** American Journal of Public Health, Vol. 92, No. 8, pp. 1254-1256.

The authors report on the analysis of a survey conducted by the New York City Department of Health of 113 agencies (4 syringe exchange programs (SEPs) and 109 drug treatment programs) on HCV counseling and screening practices. Fifty-five (50%) of the drug treatment programs and none of the SEPs reported screening for HCV infection. Of the 58 programs that did not screen, 39 (67%) cited the reason as not within the scope of services. Ninety (80%) of the 113 surveyed

programs provided hepatitis C education and counseling. Barriers to offering hepatitis C services cited were lack of educational materials and inadequate funding. The authors conclude that drug treatment programs should be provided with resources to offer hepatitis C screening programs or should be encouraged to partner with agencies that can provide screening and follow-up.

Thorpe, Lorna E.; Ouellet, Lawrence J.; Hershow, Ronald; et al. (2002) **Risk of Hepatitis C Virus Infection among Young Adult Injection Drug Users Who Share Equipment.** American Journal of Epidemiology, Vol. 155, No. 7, pp.645-653

The authors measured the incidence of HCV infection in a cohort of IDUs aged 18-30 years in Chicago, Illinois, and determined the risk of HCV seroconversion associated with specific forms of From 1997 to 1999, serum sharing injection paraphernalia. samples were screened for HCV antibodies; 27% of study participants tested positive at baseline. Seronegative participants were tested for HCV antibodies at baseline, at 6 months, and at 12 months. Twenty-nine (4%) participants seroconverted by the study's end. After controlling for demographics and drug-use covariates, and adjusting for syringe-sharing, investigators concluded that the sharing of drug "cookers," resulted in a four-fold increase in the risk of contracting HCV. Sharing cotton filters gave a 2.5-fold risk increase. The authors conclude that sharing of injection equipment other than syringes may be an important cause of HCV transmission between IDUs, and prevention messages should address all equipment-sharing practices among IDUs.